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ABSTRACT

This document consists of a compilation of fact sheets and newsletters on specific topics related to handicapped children and youth. The specific titles are as follows: (1) General Information about Handicaps and People with Handicaps; (2) Sources of Help and Information; (3) Autism; (4) Cerebral Palsy; (5) Deafness; (6) Down's Syndrome; (7) Emotional Disturbances; (8) Epilepsy; (9) Learning Disabilities; (10) Mental Retardation; (11) Severe Handicaps; (12) Speech and Language Impairments; (13) Spina Bifida; (14) Visual Impairments; (15) Physical Disabilities and Special Health Problems; (16) Work and the Severely Handicapped: The Transition for Youth; (17) Self-Advocacy: How to Be a Winner; (18) Teaching and Learning in Remote Schools: A Dilemma beyond Rural Education; (19) You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap; (20) Parents Helping Parents and Other Parent Support Activities; (21) Teaching Children with Handicaps: Some Implications; (22) Attitudes (towards students with handicaps); (23) Teacher Centers: Teachers Helping Teachers; (24) The Teacher/Parent Relationship; (25) Classroom Management; (26) Print Sources for Information; and (27) National Parent Group RoundTable (1983 proceedings). (CL)

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National Information Center for Handicapped Children and Youth

P.O. BOX 1492
WASHINGTON, D.C. 20013

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GENERAL INFORMATION ABOUT HANDICAPS AND PEOPLE WITH HANDICAPS

DEFINITION

The regulations for Public Law 94-142 (The Education for All Handicapped Children Act) list 11 types of handicaps:

1. DEAF

A hearing impairment so severe that the child is impaired in receiving linguistic information through hearing, with or without amplification.

2. DEAF-BLIND

Simultaneous hearing and visual impairments, whose combination causes such severe communication and other developmental and educational problems that the child cannot be accomodated in special education programs designed soley for deaf children or blind children.

3. HARD OF HEARING

A hearing impairment, whether permanent or fluctuating, which is less severe than the definition of "deaf" in this section.

4. MENTALLY RETARDED

Below average general intellectual functioning existing along with deficits in adaptive behavior and manifested during the developmental period.

5. MULTIHANDICAPPED

Several simultaneous impairments (such as mental retardation and blindness; mental retardation and orthopedic impairments; and so forth), the combination of which causes such severe educational problems that the child cannot be accomodated in special eduation programs designed solely for one of the impairments. (This definition does not include a deaf-blind child.)

6. ORTHOPEDICALLY IMPAIRED

A severe orthopedic impairment, including an impairment caused by a birth defect (e.g., clubfoot, absence of an extremity), an impairment caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairment from any other cause (e.g., cerebral palsy, amputations, and fractures or burns which cause contractures).

7. OTHER HEALTH IMPAIRED

An autistic condition manifested by severe communication and other developmental and educational problems; or limited strength, vitality, or alertness, due to

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chronic or acute health problems such as heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes.

8. SERIOUSLY EMOTIONALLY DISTURBED

A condition in which the individual exhibits one or more of the following characteristics over a long period of time and to a marked degree: An inability to learn which cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal or school problems. (This definition includes children who are schizophrenic.)

9. SPECIFIC LEARNING DISABILITY

A disorder of one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in a imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicap, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include a learning problem which is primarily the result of a visual, hearing, or motor handicap, of mental retardation, or of environmental, cultural, or economic disadvantage.

10. SPEECH IMPAIRED

A communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairement.

11. VISUALLY HANDICAPPED

A visual impairment, with or without correction. The definition includes both partially sighted children and blind children.

Prevalance

In the school year 1981-82, over 4.2 million children received special education and related services in public schools.

References

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Cutler, B.C. Unraveling the Special Education Maze: An Action Guide for Parents 1981 (Research Press, 2612 N. Mattis Avenue, Champaign, IL 61820, $9.95 plus $1.50 postage and handling.)

Gliedman, J. & Roth, W. The Unexpected Minority: Handicapped Children in America. 1980. (Harcourt Brace Jovanovich, Inc., 757 Third Avenue, New York, NY 10017, $17.95 plus 5% postage and handling.)

Hallahan, D. P. & Kauffman, J.M. Exceptional Children. Introduction to Special Education. Second Edition. 1982. (Prentice-Hall, Inc., Englewood Cliffs, NJ 07632, $23.95 plus $4.06 postage and handling.)

Haring, N.G. (Ed.) Exceptional Children and Youth. 1982. (Charles E. Merrill Publishing Co., Columbus, OH 43216, $23.95 plus $2.00 postage and handling.)

Institute for Information Studies. Learning to Live With Disability: A Guidebook for Families. 1980. Institute for Information Studies, 200 Little Falls Street, Suite 104, Falls Church, VA 22046, $8.00 plus $2.00 postage and handling.)

Moore, C.B. & Morton, K.G. A Reader's Guide for Parents of Children with Mental, Physical, or Emotional Disabilitites. 1976. HSA 77-5290 (National Center for Education in Maternal and Child Health, 3520 Prospect Street, N.W., Washington, DC 20007, free.)

Mopsik, S.I. & Agard, J.A. (Eds.) An Education Handbook for Parents of Handicapped Children. 1980. (Abt Books, 55 Wheeler Street, Cambridge, MA 02138, $20.00 plus $2.00 postage and handling.)

Perske, R. Hope for the Families, New Directions for Parents of Persons with Retardation or Other Disabilitites 1981. (Abingdon Press, 201 8th Avenue South, Nashville, TN 37202, $4.95 prepaid.)

Reynolds, M.C. & Birch, J.W. Teaching Exceptional Children in All America's Schools. Revised Edition. 1982. (The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091, $19.95 prepaid.)

Telford, C.W. & Sawrey, J.M. The Exceptional Individual. 1981. (Prentice-Hall, Inc., Englewood Cliffs, NJ 07632, $25.95 plus $4.58 postage and handling.)

Turnbull, A. P. & Turnbull, H.R. Parents Speak Out. Views from the Other Side of the Two Way Mirror. 1978. (Charles E. Merrill Publishing Co., Columbus, OH 43216, $11.50 plus $2.00 postage and handling.)

Zang. B. (Ed.) How to Get Help for Kids. A References Guide to Services for Handicapped Children. 1980 (Gaylord Proffesional Publications, P.O. Box 61, Syracuse, NY 13201, $29.95 plus $.50 postage and handling.)

Zukerman, L. & Yura, M.T. Raising The Exceptional Child: Meeting the Everyday Challange of the Handicapped or Retarded Child. 1979 (Hawthorn Books, 2 Park Avenue, New York, NY 10016, $11.95 plus $1.19 postage and handling.)

Resources

Alexander Graham Bell Association
for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007

American Coalition of
Citizens with Disabilities
1200 15th Street, N.W.
Washington, DC 20036

American Council for the Blind
1211 Connecticut Avenue, N.W.
Suite 506
Washington, DC 20036

American Federation for the Blind
15 West 16th Street
New York, NY 10011

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234

Association for Persons with Severe Handicaps
7010 Roosevelt Way, N.E.
Seattle, WA 98115

Association for Retarded Citizens/U.S. National Headquarters
P.O. Box 6109
2501 Avenue J
Arlington, TX 76011

Association for the Care of Children's Health
3615 Wisconsin Avenue
Washington, DC 20016

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Down's Syndrome Congress
1640 West Roosevelt Road
Chicago, IL 60608

Epilepsy Foundation of America
4351 Garden City Drive,
Landover, MD 20785

Goodwill Industries of America
9200 Wisconsin Avenue, N.W.
Bethesda, MD 20814

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605

Mental Health Association
1800 North Kent Street
Arlington, VA 22209

National Association of the Deaf
814 Thayer Avenue
Silver Springs, MD 20910

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, DC 20005

National Spinal Cord Injury Association
369 Elliot Street
Newton Upper Falls, MA 02164

Spina Bifida Association of America
343 South Dearnborn Street
Suite 319
Chicago, IL 60604

United Cerebral Palsy Association
666 East 34th Street
New York, NY 10016

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SOURCES OF HELP AND INFORMATION

There are a number of sources for more information on handicaps and related issues. This section describes some of the things you can have sent to you.

DISABLED USA

President's Committee on Employment of the Handicapped
Washington, D.C. 20210.
(Published Monthly)

Reports progress in opportunities for people with disabilities and developments in rehabilitation and employment.

THE INDEPENDENT

Center for Independent Living,
2539 Telegraph Avenue
Berkeley, CA 94704
(Published quarterly)

Articles about disabilities and up-to-date information on independent living.

REPORT

The National Center for a Barrier Free Environment
1015 15th Street, N.W. Suite 700
Washington, DC 20005
(Published bi-monthly)

News about legislation related to accessibility, news briefs and summaries of articles and books mainly concerned with barriers.

SIBLING INFORMATION NETWORK NEWSLETTER

Department of Educational Psychology
Box U-64
University of Connecticut
Storrs, CT 06268

Research and literature reviews, meetings, family relationship information of interest to siblings of youth with handicaps.

THE EXCEPTIONAL PARENT

The Exceptional Parent
296 Boylston Street
3rd Floor
Boston, MA 02116
(Published eight times yearly)

Emphasis on education, diagnosis, attitudes, care; covering all handicaps, it is directed toward parents.

THE GREEN SOURCE BOOK — NATIONAL DIRECTORY OF PRODUCTS AND SERVICES FOR THE DISABLED (Formerly entitled GREEN PAGES)

Source Book Publications
P.O. Box 1586
Winter Park, FL 32789
(Published annually)

Annual Directory of products and services. Subscription includes an occasional newsletter, "Green Papers," with legislative information and stories about people with handicaps.

UPFRONT

Mafex Associates, Inc.
90 Cherry Street, Box 519
Johnstown, PA 15907
(Published 11 times a year)

A newspaper for and about physically and mentally disabled people.

INFORMATION ABOUT HANDICAPPING CONDITIONS

Write to these agencies for information about all handicapping conditions. Specify exactly what you are interested in. Organizations dealing with specific handicapping conditions are listed on individual fact sheets.

American Civil Liberties Union
132 West 43rd Street
New York, NY 10036

American Genetics Association
818 18th Street, NW
Washington, DC 20036

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Developmental Disabilitites Office
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 338E
Washington, DC 20201

Human Resources Center
I.U. Willets Road
Albertson, NY 11507

Library of Congress
Division for Blind and Physically Handicapped
1291 Taylor Street, NW
Washington, DC 20542

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314

Office for Handicapped Individuals
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Office of Rehabilitation Services
U.S. Department of Education
Switzer Building
330 "C" Street, SW
Washington, DC 20202

President's Committee on Employment of the Handicapped
Washington, DC 20010

President's Committee on Mental Retardation
Washington, DC 20201

Special Education Programs
U. S. Department of Education
Switzer Building
330 "C" Street, SW
Washington, DC 20202

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AUTISM

Definition

According to the National Society for Children and Adults with Autism (NSAC), autism is a severely incapacitating developmental disability that usually appears during the first three years of life.

Prevalence

The rate of prevalence, or how often autism accurs in children, ranges from five to fifteen out of 10,000 births. The different estimates are based on slightly different definitions of autism.

It is four times more common in boys than girls and is rarely found in more than one child in a family.

There appear to be several causes of autism, each with distinct neurological effects. Among these causes are untreated phenylketonuria, rubella, celiac disease, and chemical exposures in pregnancy. No known factors in the psychological environment of a child have been shown to cause autism.

Characteristics

Sometimes infants show autistic behaviors from birth: they appear aloof, resist cuddling and show no interest in their surroundings. Children usually have average appearances. Typical characteristics include:

- absent or delayed speech and language, including immature speech rhythms, limited understanding, and use of words without attaching usual meanings.
- abnormal ways of relating to people, objects, and events
- unusually high or low activity levels
- insistence that the environment and routine remain unchanged
- use of toys and objects in unconventional manners
- slow development or lack of physical, social, and learning skills
- repetitive movements such as rocking and spinning, head banging, and hand twisting.

It should be noted that these characteristics may occur in children with other disabilities. Sometimes the term "autistic-like" behavior is used.

Educational Implications

Early diagnosis of autism is very important, but appropriate help given at any age can make a big difference.

The child or youth with autism appears to profit from a high degree of structure in the educational program. Such programs frequently stress social and language skills, with instruction broken down into small, sequential steps.

Although the majority of children with autism are severely delayed in learning, most can learn academic skills and social functioning in an appropriate program.

Many parents and teachers have found that behavior modification can assist the child in developing appropriate behavior.

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Balow, B., Raison, S., & Reid, G. *Revised Autism Sourcebook for Parents and Professionals*. 1980. (Special Education Programs, University of Minnesota, Minneapolis, MN)

DeMyer, M. *Parents and Children in Autism*. 1979. (John Wiley and Sons, 605 Third Avenue, New York, NY 10158)

Gillian, James E. *Autism: Diagnosis, Instruction Management, and Research*, C.C. Thomas. 1981.

Luce, S.C., & Christian, W.P. *How to Reduce Autistic and Severely Maladaptive Behaviors*. 1981. (H&H Enterprises, Inc., P.O. Box 1070 A-1, 946 Tennessee Street. Lawrence, KS 66044)

National Society for Autistic Children. *How They Grow: A Handbook for Parents of Young Children with Autism*. 1980. (National Society for Autistic Children, 1234 Massachusetts Avenue, NW, Washington, DC 20005) Available in Spanish

Paluszny, M. *Autism, A Practical Guide for Parents and Professionals*. 1979. (Syracuse University Press, 1011 E. Water Street, Syracuse, NY 13210)

Park, C.C. *The Siege*. 1967. (Harcourt, Brace and World, 757 Third Avenue, New York, NY 10017)

Rutter, M., and Schopler, E. (Eds.) *Autism: A Reappraisal of Concepts and Treatment*. 1978. (Plenum Publishing Corp., 233 Spring Street, New York, NY 10013)

Schopler, E. Mesibov. G. *Autism, in the Adolescent and Adult*. 1983. (Plenam Publishing Corp., 233 Spring Street, New York, NY 10013.

Schopler, E. *Individualized Assessment and Treatment for Autistic and Developmentally Disabled Children*. Incl. Vol. 1 Psycho-Educational Profile. 1978. Vol. 2 Teaching Strategies for parents and Professionals. 1979. (University Park Press)

Wing, L. (Ed.) *Early Childhood Autism*. 1976. (Pergamon Press, Inc., Maxwell House, Fairview Park, Elmsford, NY 10523)

Resources

Institute for Child Behavior Research
4157 Adams Avenue
San Diego, CA 92116

National Clearinghouse for Mental Health Information
National Institute of Mental Health, HHS
15C-17 Parklawn Building
5600 Fishers Lane
Rockville, MD 20857

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005-4599

NSAC Bookstore
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, DC 20005-4599

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CEREBRAL PALSY

DEFINITION

According to the United Cerebral Palsy Association, cerebral palsy is a group of disabling conditions caused by damage to the central nervous system. "Cerebral" refers to the brain, while "palsy" describes lack of muscle control that is often (but not always) a nervous system symptom. Cerebral palsy can be mild or severe.

Damage to the brain may occur before or during birth because of illness in pregnancy, premature delivery, or lack of oxygen supply to the baby; or it may occur early in life as a result of an accident, lead poisoning, illness, child abuse, or other factors.

PREVALENCE

Approximately 700,000 Americans (or 16 out of every 5,000) have some degree of cerebral palsy. 10,000 babies with the disorder are born each year, and another 2,000 acquire it in the early years of life.

CHARACTERISTICS

Four main descriptions of cerebral palsy have been identified:

1. Spastic, the most common type, which results in tense, contracted muscles;
2. Athetoid, which is characterized by constant uncontrolled movements; and
3. Ataxic, which is typified by poor sense of balance and depth perception.
4. A combination of the types of cerebral palsy listed above.

The effects of cerebral palsy depend on the extent and location of the brain damage. One or more of the following conditions may occur:

- seizures
- problems in vision, hearing or speech

- abnormal sensation or perception
- mental retardation
- impairments in arm and leg movement

EDUCATIONAL IMPLICATIONS

Early identification of cerebral palsy can lessen developmental problems and lead to appropriate treatment when it helps the most. Special educators and physicians have discovered that early intervention can make an important difference. Early intervention programs enlist parents and other family members in working with the child in specific activities. These activities designed by therapist, provide the child with stimulation needed to overcome slower development which is part of cerebral palsy. Other forms of treatment of children with cerebral palsy may include speech and language therapy, occupational therapy, physical therapy, medical intervention and social services.

Among the services that the older child with cerebral palsy may need are: attendant care, continuing therapy, special education, counseling, vocational training, and recreation training. The services needed will vary from child to child depending on the nature and severity of their handicap.

Important advances have taken place in the last decade which have a great affect on the long term well-being of children born with cerebral palsy. Advanced technology is being applied to the needs of severely disabled persons with cerebral palsy. Advanced technology such as the use of biofeedback, computers or engineering devices has provided assistance in learning and living. Technological innovations made have been made in the areas of speech and communication, self-care, and adapting jobs. The future may bring even more significant applications.

The other important development has been an increased ability of disabled person including those who are severely disabled to live independently in the community. Independent living opportunities exist in the form of group, shared and supervised apartments, and disabled individual living on their own in the community with appropriate support services. Independent Living Centers staffed and run by persons with disabilities have proven to be important resources for disabled persons. Treatment of cerebral palsy has emerged to be a combination between educational, medical and social services.

References

Bigge, J. L. Teaching Individuals With Physical and Multiple Disabilities. Second Edition. 1982. (Charles E. Merril Publishing Co., Columbus, OH 43216, $24.95 plus $2.00 postage and handling.)

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Cruickshank, W. M. (Ed.) Cerebral Palsy: A Developmental Disability. Third Edition. 1976. (Syracuse University Press, 1600 Jamesville Avenue, Syracuse, NY 13210, $26.00 plus $1.25 postage and handling.)

Finnie, N.R. Handling The Young Cerebral Palsied Child at Home. Second Edition. 1975. (E. P. Dutton and Co., 2 Park Avenue, New York, NY 10016, $6.31 plus $.63 postage and handling.)

Garwood S., et.al. Educating Young Handicapped Children: A Developmental Approach. 1979 (Aspen System Corporation, 1600 Research Blvd, Rockville, MD 20850.)

Institute for Information Studies. Learning to Live With Disability: A Guidebook for Families. 1980. (Institute for Information Studies, 200 Little Falls Street, Suite 104, Falls Church, VA 22046, $8.00 plus $2.11 postage and handling.)

Moore, C.B., & Morton, K.G. A Reader's Guide to Parents of Children With Mental, Physical or Emotional Disabilities. 1976. (ERIC Document Production Service, P.O. Box 190, Arlington, VA 22210. ED 143179 $10.90 plus $1.97 shipping charge.)

Prensky, A. L. & Pulkes, H. S. Care of the Neurologically Handicapped Child. A Book for Parents and Professionals. 1982. (Oxford University Press, 200 Madison Avenue, New York, NY 10016, $24.95 prepaid.)

Resources

Information on Cerebral Palsy

United Cerebral Palsy Associations
66 East 34th Street
New York, NY 10016
(212) 481-6300

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
(312) 243-8400

National Institute for Neurological and Communicative Disorders and Stroke
National Institute of Health, HHS
Building 31, Room 8A-06
Bethesda, MD 20205
(301) 496-5751

Information of Special Education

ERIC Clearinghouse on the Handicapped and Gifted
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Information on Equipment for Children with Disabilities

ABELEDATA
c/o National Rehabilitation
Information Center
4407 8th Street NE
Washington, DC 20017
(202) 635-6090

Accent on Information
P.O. Box 700
Gillum Road and High Drive
Bloomington, IL 61701
(309) 378-2961

Information on Design of Accessible Facilities

National Center for a Barrier Free
Environment
1015 - 15th Street, N.W.
Washington, DC 20036
(202) 466-6896

Adaptive Environments Center
Massachusetts College of Art
26 Overland Street
Boston, MA 02215
(617) 266-2666

Information on Communication Aids

Trace Center Research and Development
Center
314 Waisman Center
1500 Highland Avenue
Madison, WI 53706
(608) 262-6966

Information on Rehabilitation and Independent Living

National Rehabilitation Information
Center
4407 8th Street, N.E.
Washington, DC 20007
(202) 635-5822

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Gallaudet College/National Information Center on Deafness

NICD/NAD

DEAFNESS: A FACT SHEET

FROM THE NATIONAL INFORMATION CENTER ON DEAFNESS AND THE NATIONAL ASSOCIATION OF THE DEAF

Introduction

An estimated 16 million Americans have some degree of hearing impairment. Hearing impairments affect individuals of all ages, and may occur at any time from infancy through old age. The degree of loss may range from mild to severe. This variability in age at onset and degree of loss plus the fact that each individual adjusts differently to a loss of hearing makes it impossible to define uniformly the consequences of a loss.

Of the 16 million Americans who are hearing impaired, over two million are considered deaf. These individuals have hearing losses so severe that they cannot hear or understand either speech or most of the sounds in our everyday environment, even with the help of a hearing aid. The other 14 million hearing impaired Americans have less severe losses and often can be helped to understand speech through the use of a hearing aid.

Audiological/Medical Information

There are four types of hearing loss, each of which can result in different problems and different possibilities for medical and non-medical remediation.

Conductive hearing losses are caused by diseases or obstructions in the outer or middle ear (the conduction pathways for sound to reach the inner ear). Conductive hearing losses usually affect evenly all frequencies of hearing and do not result in severe losses. A person with a conductive hearing loss usually is able to use a hearing aid well, or can be helped medically or surgically.

Sensorineural hearing losses result from damage to the delicate sensory hair cells of the inner ear or the nerves which supply it. These hearing losses can range from mild to profound. They often affect certain frequencies more than others. Thus, even with amplification to increase the sound level, the hearing-impaired person perceives distorted sounds. This distortion accompanying some forms of sensorineural hearing loss is so severe that successful use of a hearing aid is impossible.

Mixed hearing losses are those in which the problem occurs both in the outer or middle and the inner ear.

A **central** hearing loss results from damage or impairment to the nerves or nuclei of the central nervous system, either in the pathways to the brain or in the brain itself.

Among the causes of deafness are heredity, accident, and illness. An unborn child can inherit hearing loss from the parents. In about 50% of all cases of deafness, genetic factors are a probable cause of deafness. Environmental factors (accident, illness, ototoxic drugs, etc.) are responsible for deafness in the remaining cases. Rubella or other viral infections contracted by the pregnant mother may deafen an unborn child. Hazards associated with the birth process (for example, a cut-off in the oxygen supply) may affect hearing. Illness or infection may cause deafness in young children. Constant high noise levels can cause progressive and eventually severe sensorineural hearing loss as can tumors, exposure to explosive sounds, heavy medication, and/or injury to the skull or ear.

Central hearing loss may result from congenital brain abnormalities, tumors, or lesions of the central nervous system, strokes, or some medications that specifically harm the ear.

The detection and diagnosis of hearing impairment have come a long way in the last few years. It is now possible to detect the presence of hearing loss and evaluate its severity in a newborn child. While medical and surgical techniques of correcting conductive hearing losses have also improved, medical correction for sensorineural hearing loss has been more elusive. Current research on a cochlear implant which provides electrical stimulation to the inner ear may lead to important improvements in the ability to medically correct profound sensorineural hearing loss.

Educational Implications

Deafness itself does not affect a person's intellectual capacity or ability to learn. Yet, deaf children generally require some form of special schooling in order to gain an adequate education.

Deaf children have unique communication needs: unable to hear the continuous, repeated flow of language interchange around them, deaf children are not automatically exposed to the enormous amounts of

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language stimulation experienced by hearing children during their early years. For deaf children, early, consistent, and conscious use of visible communication modes (such as sign language, fingerspelling, and Cued Speech) and/or amplification and aural/oral training can help reduce this language delay. Without such assistance from infancy, problems in the use of English typically persist throughout the deaf child's school years. With such assistance, the language learning task is easier but by no means easy.

This problem of English language acquisition affects content areas as well. While the academic lag may be small during the primary grades, it tends to be cumulative. A deaf adolescent may be a number of grade levels behind hearing peers. However, the extent to which hearing impairment affects school achievement depends on many factors—the degree and type of hearing loss, the age at which it occurred, the presence of additional handicaps, the quality of the child's schooling, and the support available both at home and at school.

Many deaf children now begin their education between ages one to three in a clinical program with heavy parent involvement. Since the great majority of deaf children—over 90%—are born to hearing parents, these programs provide instruction for parents on implications of deafness within the family. By age four or five, most deaf children are enrolled in school on a full-day basis. Approximately one-third of school-age deaf children attend private or public residential schools. Some attend as day students and the rest usually travel home on weekends. Two-thirds attend day programs in schools for the deaf or special day classes located in regular schools, or are mainstreamed into regular school programs. Some mainstreamed deaf children do most or all of their schoolwork in regular classes, occasionally with the help of an interpreter, while others are mainstreamed only for special activities or for one or two classes.

In addition to regular school subjects, most programs do special work on communication and language development. Class size is often limited to approximately eight children to give more attention to the children's language and communication needs.

At the secondary school level, students may work toward a vocational objective or follow a more academic course of study aimed at postsecondary education at a regular college, a special college program for deaf students (such as Gallaudet College or the National Technical Institute for the Deaf), or one of the 100 or more community colleges and technical schools that have special provisions for deaf students.

Communication: Some Choices

Communication is an important component of everyone's life. The possible choices for communication involve a variety of symbol systems. For example, you may communicate in English through speaking and writing. Despite your skills, you probably cannot communicate with someone whose only language is Chinese, even though that person also speaks, reads, and writes quite fluently.

In the United States, deaf persons also use a variety of communication systems. They may choose among speaking, speechreading, writing, and manual communication. Manual communication is a generic term referring to the use of manual signs and fingerspelling.

American Sign Language

American Sign Language (ASL) is a language whose medium is visible rather than aural. Like any other language, ASL has its own vocabulary, idioms, grammar and syntax—*different from English.* The elements of this language (the individual signs) consist of the handshape, position, movement, and orientation of the hands to the body and each other. ASL also uses space, direction and speed of movements, and facial expression to help convey meaning.

Fingerspelling

When you spell with your fingers, you are in effect "writing in the air." Instead of using an alphabet written on paper, you are using a manual alphabet, that is, one with handshapes and positions corresponding to each of the letters of the written alphabet.

Conversations can be entirely fingerspelled. Among deaf people, however, fingerspelling is more typically used to augment American Sign Language. Proper names and terms for which there are no signs are usually fingerspelled. In the educational setting, the use of fingerspelling as the primary mode of communication in combination with spoken English is known as the Rochester method.

Manual English

When the vocabulary of the American Sign Language and fingerspelled words are presented in English word order, a 'pidgin' results. Pidgin Sign English (PSE) is neither strictly English nor ASL, but combines elements of both.

A number of systems have recently been devised to assist deaf children in learning English. These systems supplement some ASL signs with invented signs that correspond to elements of English words (plurals, prefixes, and suffixes, for example). There is usually a set of rules for word (sign) formation within the particular system. These systems are generically known as manually-coded English or manual English systems. The two most commonly used today are Signing Exact English and Signed English. While each of these systems was devised primarily for use by parents and in the educational setting, many of the invented and initialized signs from their lexicon are filtering into the vocabulary of the general deaf community.

Oral Communication

This term denotes the use of speech and speechreading as the primary means for communication with deaf persons. Educators who believe in the oral communication philosophy, in their work with deaf children, emphasize exclusively the teaching of speech and speechreading (lipreading) together with amplification and the use of whatever residual hearing the child has.

Speechreading

Recognizing spoken words by watching the speaker's lips, face, and gestures is a daily challenge for all deaf persons. Speechreading is the least consistently visible of the communication choices available to deaf people: only about 30% of English sounds are visible on the lips, and 50% are homophonous, that is, they look like something else. Try it for yourself. Look in a mirror and "say" without voice the words 'kite', 'height', 'night.' You'll see almost no changes on your lips to distinguish among those three words. Then say the following three words—'maybe', 'baby', 'pay me.' They look exactly alike on the lips.

Some deaf people become skilled speechreaders especially if they can supplement what they see with some hearing. Many do not develop great skill at speechreading, but most deaf people do speechread to some extent. Because speechreading requires guesswork, very few deaf people rely on speechreading alone for exchanges of important information.

Cued Speech

Cued Speech is a system of communication in which eight hand shapes in four possible positions supplement the information visible on the lips. The hand "cue" signals a visual difference between sounds that look alike on the lips—such as /p/, /b/, /m/. These cues enable the hearing-impaired person to *see* the phonetic equivalent of what others hear. It is a speech-based method of communication aimed at taking the guesswork out of speechreading.

Simultaneous Communication

This term denotes the combined use of speech, signs, and fingerspelling. Simultaneous communication offers the benefit of seeing two forms of a message at the same time. The deaf individual speechreads what is being spoken and simultaneously reads the signs and fingerspelling of the speaker.

Total Communication

Total Communication is a philosophy which implies acceptance and use of all possible methods of communication to assist the deaf child in acquiring language and the deaf person in understanding.

Historically, proponents of particular systems have often been at odds with proponents of other systems or modes. There is increasing consensus that whatever system or systems work best for the individual should be used to allow the hearing-impaired person access to clear and understandable communication.

Deaf Adults in Today's Society

The deaf adult population in the United States is composed both of individuals deaf since early childhood and individuals who lost their hearing later in life. Persons who were deafened as adults, or after the age of 18, are sometimes called post-vocationally deaf. Having already embarked on their careers, these persons may have serious problems both personally and professionally adjusting to their hearing loss. Persons who were deafened prior to age 18 may have different problems. Those with early onset deafness may have problems not only with English language skills, but also, because of fewer opportunities for interaction with hearing people in pre-work settings, they may be less well prepared for interpersonal relationships they encounter in the job market.

Discrimination is a common problem for minority groups. Deaf persons, as members of a minority group, experience their share of discrimination. Deaf people as a group are **underemployed.** Together with members of other minority and/or disabled groups, deaf people are working to change attitudes which have given them jobs but less access to advancement opportunities.

In the United States, deaf persons work in almost every occupational field. Some have become doctors, dentists, lawyers, and members of the clergy. A number of deaf persons enter careers within the field of deafness. Thirteen hundred teachers of the deaf in the United States are themselves hearing impaired. In addition, there are deaf administrators, psychologists, social workers, counselors, and vocational rehabilitation specialists. Deaf people drive cars and hold non-commercial pilot's licenses and pursue the same leisure time interests as everyone else.

Many deaf young people have attended school with deaf classmates. This educational pattern coupled with ease of communication and compatibility encouraged by shared experiences as deaf individuals leads to socializing with other deaf individuals in maturity. Many deaf people (80%) tend to marry other deaf persons; most of their children (approximately 90%) are hearing.

The Deaf Community

Because the problem in dealing with the hearing world is one of communication, deaf persons tend to socialize together more than do persons with other disabilities. However, members of the deaf community have contacts with other people, too. Some are active members of organizations of hearing people. Some deaf people move freely between hearing and deaf groups, while other deaf people may have almost no social contact with hearing people. A few deaf people may choose to socialize only with hearing people.

While it is possible to find deaf individuals in every section of the United States, there are major concentrations of deaf persons in the larger metropolitan areas of the East and West Coasts.

Organizations of and for Deaf Persons

Clubs and organizations of deaf persons range in purpose from those with social motives (watching captioned films, for example) to those with charitable aims. Organizations offer deaf persons the opportunity to pursue a hobby (athletics, drama) or civic commitment (political action) on the local, regional or national level. Local or state associations of deaf persons may be affiliated with the National Association of the Deaf. The Oral Deaf Adults Section of the Alexander Graham Bell Association for the Deaf has local chapters that provide social opportunities for deaf people who favor oral communication. The National Fraternal Society of the Deaf, with insurance, social and charitable objectives, has 120 divisions throughout the United States and Canada.

A few of the more than 20 national organizations of and for deaf persons in the United States are briefly described in the following listing. Many of these organizations publish newsletters, magazines, or journals. Add to these the publications developed by clubs and schools for the deaf (for students and alumni) and it is possible to identify 400 publications aimed at a readership within the deaf community.

Alexander Graham Bell Association for the Deaf
3417 Volta Place, NW
Washington, DC 20007
(202) 227-5220 (V/TDD)

A private, non-profit organization serving as an information resource, advocate, publisher, and conference organizer, the Alexander Graham Bell Association is committed to finding more effective ways of teaching deaf and hard of hearing persons to communicate orally. Sections within the organization focus on the needs of deaf adults (Oral Deaf Adults Section) and parents (International Parent Organization).

American Deafness and Rehabilitation Association
814 Thayer Avenue
Silver Spring, MD 20910
(301) 589-0880 (V/TDD)

An interdisciplinary organization for professional and lay persons concerned with services to adult deaf persons, ADARA sponsors workshops for state rehabilitation coordinators.

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, MD 20910
(301) 585-5400 (V/TDD)

Composed of parents and concerned professionals, ASDC provides information, organizes conventions, and offers training to parents and families with children who are hearing impaired.

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788 (V/TDD)

With 50 state association affiliates and an aggregate membership exceeding 20,000, the NAD is a consumer advocate organization concerned about and involved with every area of interest affecting life opportunities for deaf persons. It serves as a clearinghouse of information on deafness, offers for sale over 200 books on various aspects of deafness, and works cooperatively with other organizations representing both deafness and other disabilities on matters of common concern.

Educational Institutions

Schools for deaf students have traditionally played an important role in advancing the welfare of deaf people through education of deaf students and public information efforts about the capabilities and accomplishments of deaf people. Two national institutions each have enrollments of over 1,000 deaf students.

Gallaudet College
800 Florida Avenue, NE
Washington, DC 20002

National Technical Institute for the Deaf
Rochester Institute of Technology
1 Lomb Memorial Drive
Rochester, NY 14623

For descriptions of the more than 100 postsecondary programs for deaf students at community colleges and technical schools around the country, order a copy of **College and Career Programs for Deaf Students** for $3.50 from:

College and Career Guide
c/o Gallaudet Research Institute
Center for Assessment and Demographic Studies
800 Florida Avenue, NE
Washington, DC 20002

Special Devices for Deaf People

Technology and inventiveness have lead to a number of devices which aid deaf persons and increase convenience in their daily lives. Many of these devices are commercially available under different trade names.

Telecommunications Devices for Deaf People (TDDs) are mechanical/electronic devices which enable people to type phone messages over the telephone network. The term TDD is generic and replaces the earlier term TTY which refers specifically to teletypewriter machines. Telecaption adapters, sometimes called decoders, are devices which are either added to existing television sets or built into certain new sets to enable viewers to read dialogue and narrative as captions (subtitles) on the TV screen. These captions are not visible without such adapters.

Signalling Devices which add a flashing and/or vibrating signal to the existing auditory signal are popular with hearing impaired users. Among devices using flashing light signals are door "bells", telephone ring signallers, baby-cry signals (which alert the parent that the baby is crying), smoke alarm systems. Alarm clocks may feature either the flashing light or vibrating signal.

Some Special Services

Numerous social service agencies extend their program services to deaf clients. In addition, various agencies and organizations—either related to deafness or to disability in general—provide specific services to deaf people. Among these special services are the following:

Captioned Films for the Deaf
A loan service of theatrical and educational films captioned for deaf viewers, Captioned Films for the Deaf is one of the projects funded by the Captioning and Adaptations Branch of the U.S. Department of Education to promote the education and welfare of deaf people through the use of media. This branch also provides funds for closed-captioned television programs, including the live-captioned ABC-TV news.

Registry of Interpreters for the Deaf, Inc.
A professional organization, RID maintains a national listing of individuals skilled in the use of American Sign Language and other sign systems and provides information on interpreting and evaluation and certification of interpreters for deaf people.

State Departments of Vocational Rehabilitation
Each state has specific provisions for the type and extent of vocational rehabilitation service, but all provide vocational evaluation, financial assistance for education and training, and job placement help.

Telecommunications for the Deaf, Inc.
TDI publishes an international telephone directory of individuals and organizations who own and maintain TDDs (telecommunications devices for deaf people) for personal or business use.

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Suggested Readings

Davis, H. and Silverman, R.S. **Hearing and Deafness** (4th ed.) New York: Holt, Rinehart and Winston, 1978.

Freeman, R., Carbin, C.F., and Boese, R. **Can't Your Child Hear? A Guide for Those Who Care About Deaf Children**. Baltimore: University Park Press, 1981.

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Schlesinger, H. and Meadow, K. **Sound and Sign: Childhood Deafness and Mental Health.** Berkeley: University of California, 1974.

Spradley, T. S. and Spradley, J. P. **Deaf Like Me.** New York: Random House, 1978

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Directory of Services

The April issue of the **American Annals of the Deaf** is a directory of the various programs and services for deaf persons in the United States. Copies of this reference may be purchased from:

American Annals of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910

Additional Information

If you have specific questions that were not answered by this fact sheet, please contact either the National Information Center on Deafness, Gallaudet College, Washington, DC 20002, or the National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910.

The National Information Center on Deafness (NICD) is a centralized source of information on all aspects of deafness, including education, vocational training, sign language programs, law, technology, and barrier-free design.

1984 DIRECTORY
NATIONAL ORGANIZATIONS AND CENTERS OF AND FOR THE DEAF

ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF, INC.
EXEC. DIRECTOR—Sara E. Conlon
3417 Volta Place, N.W.
Washington, D.C. 20007
Voice and TDD: (202) 337-5220
PRESIDENT—William Castle, Ph.D.
PUBLICATIONS—*Volta Review* (journal)
Newsounds (newsletter-7 times a year)
Editor-Richard Kretschmer-*Volta Review*
Genie Doggett-*Newsounds*

Committed to speech education for hearing impaired and deaf people. Disseminates informational materials to all interested persons.

AMERICAN ATHLETIC ASSOCIATION OF THE DEAF
PRESIDENT—Richard E. Caswell
3916 Lantern Drive
Silver Spring, Maryland 20902
Voice and TDD: (301) 942-4042 (H)
(202) 224-8637 (W)
PUBLICATION:*AAAD Bulletin* (quarterly)
Editor—Cole Zulauf

Promotes athletic tournaments in the U.S. and coordinates United States involvement in international competitions.

AMERICAN COALITION OF CITIZENS WITH DISABILITIES
Suite 201, 1200 15th Street N.W.,
Washington, D.C. 20005
Voice: (202) 785-4265
TDD: (202) 785-4341
PRESIDENT—Phyllis Rubenfeld
PUBLICATION-*ACCD NewsNet* (monthly)

A national non-profit membership coalition representing the needs of all disabled persons in this country.

AMERICAN DEAFNESS AND REHABILITATION ASSOCIATION (formerly Professional Rehabilitation Workers with Adult Deaf)
EXEC.DIRECTOR—Sharon H. Carter
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 589-0880
PRESIDENT—Eugene Peterson
PUBLICATIONS—*Journal of Rehabilitation of the Deaf* (quarterly); *ADARA Newsletter* (quarterly)

A membership organization and network which promotes, develops and expands services, research and legislation to deaf persons.

AMERICAN SOCIETY OF DEAF SOCIAL WORKERS
PRESIDENT—Sanremi I. LaRue
c/o Bernice Hoeper
8716 Hayshed Lane
Columbia, Maryland 21045

Promotes information sharing and upgrades the professional standards among hearing impaired social workers and hearing social workers who work primarily with the hearing impaired.

CAPTIONED FILMS FOR THE DEAF
Modern Talking Pictures Service, Inc.
5000 Park Street North
St. Petersburg, Florida 33709
Voice and TDD: (800) 237-6213

Loans educational and entertainment captioned films. Distributes materials for advocacy and for use in education of handicapped individuals.

CONFERENCE OF EDUCATIONAL ADMINISTRATORS SERVING THE DEAF
EXEC. DIRECTOR—Hugh D. Summers
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 585-4363
PRESIDENT—Bill J. Peck

An organization committed to the improvement of management in programs for the deaf and the maintenance of a continuing of educational options for deaf people.

CONVENTION OF AMERICAN INSTRUCTORS OF THE DEAF
EXEC. DIRECTOR—Hugh D. Summers
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 585-4363
PRESIDENT: Dr. Gerilee Gustason
PUBLICATIONS—*American Annals of the Deaf* (bi-monthly plus special issues) *Advocate for Education of the Deaf* (bimonthly)
Editors—*AAD*-McCay Vernon; April *AAD*-Drs. Bill and Helen Craig;
ADVOCATE-Hugh D. Summers

An organization which promotes professional development, communication and information among educators of the deaf.

DEAFNESS RESEARCH FOUNDATION
EXEC. DIRECTOR—Albert J. Levine
55 East 34th Street
New York, New York 10016
Voice: (212) 684-6556
TDD: (212) 684-6559
PRESIDENT—Frank T. Reilly
PUBLICATION—*Receiver* (3 times a year)
Editor—Nan Mizrachi

Supports and provides grants for research into causes, treatment and prevention of deafness to hospitals, universities and nonprofit institutions.

DEAFPRIDE, INC.
EXEC. DIRECTOR—Ann Champ-Wilson
2010 Rhode Island Avenue, N.E.
Washington, D.C. 20018
Voice and TDD: (202) 635-2050
PRESIDENT—Barbara M. Kannapell

A non-profit, advocacy organization which works for the human rights of deaf people and their families. Assists groups to organize and work together for change in the District of Columbia and throughout the United States.

EPISCOPAL CONFERENCE OF THE DEAF
EXEC. SECRETARY—Rev. Arthur R. Steidemann
429 Somerset Avenue
St. Louis, Missouri 63119
Voice and TDD: (314) 961-1805
PRESIDENT—The Ven. Camille L. Desmarais
PUBLICATION—*The Deaf Episcopalian* (quarterly)
Editor—Rev. Arthur R. Steidemann

Promotes ministry for deaf persons throughout the Episcopal Church. Affiliated with approximately 50 congregations in the United States.

GALLAUDET COLLEGE ALUMNI ASSOCIATION
EXEC. SECRETARY—Jack R. Gannon
Alumni House, Gallaudet College
Washington, D.C. 20002
Voice: (202) 651-5277
TDD: (202) 651-5105
PUBLICATION:*Gallaudet Alumni Newsletter* (semi-monthly, Oct.-June, no Dec. issue)
Editor—Jack R. Gannon

A membership organization which supports Gallaudet College through fellowships, fund raising, national awards and oversees the College's Hall of Fame.

HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS
FOUNDER—Peter J. Salmon
DIRECTOR—Martin A. Adler
111 Middle Neck Road
Sands Point, New York 11050
Voice and TDD: (516) 944-8900
PUBLICATION—*The Nat-Cent News* (3 times a year)
Editor—Robert J. Smithdas

The single national facility which provides comprehensive evaluation and pre-vocational rehabilitation training; conducts extensive network of field services through Regional Offices, Affilitated Programs, and National Training Teams; maintains National Register of Deaf/Blind Persons; designs and improves sensory aids.

INTERNATIONAL ASSOCIATION OF PARENTS OF THE DEAF
EXEC. DIRECTOR—Jacqueline Z. Mendelsohn
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 585-5400
PRESIDENT—Patricia S. Brown
PUBLICATION-*The Endeavor* (bi-monthly)
Editor-Jacqueline Z. Mendelsohn

Membership organization providing information and support to parents and families with children who are deaf or hard of hearing.

INTERNATIONAL CATHOLIC DEAF ASSOCIATION
PRESIDENT—Arvilla Rank
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 588-4009
PUBLICATION—*The Deaf Catholic* (bimonthly)
Editor—Fred R. Murphy

Promotes ministry for Catholic deaf persons. Responds to spiritually related requests worldwide.

INTERNATIONAL LUTHERAN DEAF ASSOCIATION

SECRETARY FOR DEAF MINISTRY—
Rev. Donald W. Zuhn
1333 S. Kirkwood Road
St. Louis, Missouri 63122
Voice: (314) 965-9000
PRESIDENT—Charles Kotal
PUBLICATION—*The Deaf Lutheran* (monthly)
Editor—Archie Marshall

Promotes ministry for deaf persons throughout the Lutheran Church-Missouri Synod.

JUNIOR NATIONAL ASSOCIATION OF THE DEAF

YOUTH RELATIONS DIRECTOR—Teresa M. Ezzell
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 587-1788
PUBLICATION—*Junior Deaf American* (3-4 times a year)
Editor—Teresa M. Ezzell

Develops leadership skills among deaf high school students by creating opportunities where students can get "hands-on" experience through participation in various activities.

NATIONAL ASSOCIATION OF THE DEAF

EXEC. DIRECTOR—Albert T. Pimentel
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 587-1788
PRESIDENT—T. Alan Hurwitz
PUBLICATIONS—*The Broadcaster, The Deaf American* (monthly)
Editor—Muriel Horton-Strassler

A consumer-oriented membership organization which works on behalf of deaf people. Concerned with communication skills, legislation, employment rights and other topics of interest.

NATIONAL ASSOCIATION OF HEARING IMPAIRED COLLEGE STUDENTS

PRESIDENT—David J. Nelson
Box 1527
25 Andrew Memorial Drive
Rochester, New York 14623
TDD: (716) 475-6277 (leave message at Message Desk)
PUBLICATION—*NAHICS Newsletter*

An organization set up to foster communication and support to hearing impaired students attending colleges and universities across the United States.

NATIONAL CAPTIONING INSTITUTE, INC.

PRESIDENT—John Ball
5203 Leesburg Pike
Falls Church, Virginia 22041
Voice and TDD: (703) 998-2400

Provides closed captions for programs broadcasting each week on network television.

NATIONAL CATHOLIC OFFICE OF THE DEAF

EXEC. DIRECTOR—Sr. M. Alvena Hollis
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 587-7992
CHAIRMAN OF BOARD—Rev. Thomas Erdle
PUBLICATION-*Listening* (5 times a year)
Editor-Sister M. Alvema Hollis

Organizes workshops and provides information and teaching materials for religious education of the hearing impaired.

NATIONAL CENTER FOR LAW AND THE DEAF

LEGAL DIRECTOR—Sy DuBow
Gallaudet College
Washington, D.C. 20002
Voice and TDD: (202) 651-5454
PUBLICATION—*NCLD Newsletter* (quarterly)

Develops and provides a variety of legal services and programs to the deaf community.

NATIONAL CONGRESS OF JEWISH DEAF

EXEC. DIRECTOR—Alexander Fleischman
9102 Edmonston Court
Greenbelt, Maryland 20770
TDD: (301) 345-8612
PRESIDENT—Kenneth Rothschild
PUBLICATION—*N.C.J.D.* (quarterly)
Editor—Bess Hyman

Advocates religious and cultural ideals and fellowship for Jewish deaf persons.

NATIONAL CRISIS CENTER FOR THE DEAF

MANAGER—Mary V. Compton
University of Virginia Medical Center
Box 434
Charlottesville, Virginia 22908
Voice and TDD: 1-800-446-9876 (U.S.)
Voice and TDD: 1-800-552-3723 (Va.)

Provides emergency medical service and health information via 24-hour toll free TDD number.

NATIONAL FRATERNAL SOCIETY OF THE DEAF

GRAND PRESIDENT—Frank B. Sullivan
1300 Northwest Highway
Mt. Prospect, Illinois 60056
Voice: (312) 392-9282
TDD: (312) 392-1409
PUBLICATION—*The Frat* (bi-monthly)
Editor—Frank B. Sullivan

Works in the area of insurance and advocacy for deaf persons.

NATIONAL HEARING AID SOCIETY

PRESIDENT—William L. Syers
20361 Middlebelt Road
Livonia, Michigan 48152
Voice: (313) 478-2610
(800) 521-5247-Hearing Aid Helpline

Sets training and ethical standards for hearing aid dispensers. Provides consumer information through toll free Hearing Aid Helpline.

*NATIONAL INFORMATION CENTER ON DEAFNESS

DIRECTOR—Loraine DiPietro
Gallaudet College
Washington, D.C. 20002
Voice: (202) 651-5109
TDD: (202) 651-5976

Provides information about deafness and Gallaudet College to all interested people.

THE NATIONAL THEATRE OF THE DEAF

DIRECTOR—David Hays
The Hazel E. Stark Center
Chester, Connecticut 06412
Voice: (203) 526-4971
TDD: (203) 526-4974
ADMINISTRATOR (Professional School)-Andrew J. Vasnick
ADMINISTRATOR (Deaf Playwright's Conference)-Shanny Mow
PUBLICATION: *NTD Newsletter*

Concerned with artistic and theatrical professional development of deaf actors and actresses. Tours the U.S. and abroad. Also mounts Little Theatre of the Deaf productions.

REGISTRY OF INTERPRETERS FOR THE DEAF, INC.

EXEC. DIRECTOR—W.F. Roy III
814 Thayer Avenue
Silver Spring, Maryland 20910
Voice and TDD: (301) 588-2406
PRESIDENT—Dennis Cokely
PUBLICATIONS-*Interpreter Views* (6-times a year); *RID Interpreting Journal* (twice a year)

Professional organization which provides information on interpreting, evaluation and certification requirements for interpreters.

TELECOMMUNICATIONS FOR THE DEAF, INC.

814 Thayer Avenue,
Silver Spring, Maryland 20910
Voice and TDD: (301) 589-3006
PRESIDENT—Robert O. Lankenau
PUBLICATION—*GA-SK* (quarterly)

Adapts and installs TDDs and decoders for deaf people. Supports legislation and advocates the use of TDDs in the public sector.

U.S. DEAF SKIERS ASSOCIATION, INC.

PRESIDENT—Donald Fields
159 Davis Avenue
Hackensack, New Jersey 07601
TDD: (201)489-3777
PUBLICATION—*USDSA Newsletter* (3 times a year);
Editor—Ellen Roth

Works with U.S. teams involved in international competition. Also promotes recreational skiing for hearing impaired people.

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National Information Center on Deafness (NICD) and the Gallaudet College Alumni Association (GCAA)
Please send changes or corrections to NICD*

Rochester Institute of Technology
National Technical Institute for the Deaf

One Lomb Memorial Drive
Post Office Box 9887
Rochester, New York 14623

The latest developments
in the education of
deaf people ...
written for specialists in the education of
deaf people

NEWS · BRIEFS

Teaching Deaf Students? They May Have Hidden Vision Problems!

Dr. Donald Johnson and Dr. Frank Caccamise have completed a three-year study of nearly 1,000 hearing-impaired college students. The results show that nearly 20 percent had visual problems or pathologies of which they were either unaware or didn't understand the implications in terms of their need for medical/non-medical remediation.

Here are some of their findings:

Hearing-impaired People Have More Visual Problems Than the General Population

Studies show there's a much higher rate of visual impairments among hearing-impaired people than in the general population.

The National Society to Prevent Blindness (NSPB) says that about 25 percent of the general population of school-age children need professional attention because of suspected visual impairment. Figures from three years of research conducted at NTID from 1977-79 place the percentage of visual impairments and eye diseases among its hearing-impaired population much higher -- about 65 percent.

Many causes of hearing impairments may also result in concomitant visual impairments. Two of these diseases are maternal rubella (German measles contracted by the mother especially during the first trimester of pregnancy), and Retinitis Pigmentosa (RP) together with inherited hearing loss -- a condition referred to as Usher's Syndrome.

About seven percent of those with eye diseases that haven't yet caused functional visual problems need periodic professional attention since the disease could eventually cause permanent functional visual problems because of recurrence or the progressive nature of the disease processes. Examples of these functional visual problems are near and/or far vision deficits, color defectiveness, night blindness, narrowed visual fields, and binocular vision problems.

Visual Screening

Visual screening was conducted on the 518 new deaf students entering NTID at RIT this summer. When the final tabulations were in, we found that 22.2 percent (N=115) of these students needed an on-campus ophthalmological examination because of suspected functional visual problems or eye diseases that may need professional attention.

Three Major Visual Impairments

Functional visual problems such as these are among the most prevalent:

- Binocular Vision = The ability of the two eyes to function together to produce a single image and depth perception.
- Far and Near Visual Acuity = The ability of the eye to resolve or differentiate detail of objects viewed at a distance or close range.
- Color Defectiveness (color blindness) = An inability to discriminate certain colors (e.g., reds and greens). Other colors may be discriminated normally. These problems may be inherited or acquired.

This material was produced in the course of an agreement between Rochester Institute of Technology and the U.S. Department of Education.

The breakdown on these functional visual problems among all NTID students includes approximately 49 percent with far and/or near visual acuity problems, four percent with color defects, and 11 percent with binocular vision problems. A few of the students had combinations of these three problems. They were accounted for in the category most likely to hinder their academic success if not corrected.

Many acuity problems can be treated through the use of eyeglasses. Others can be treated through different types of medical intervention. However, there is no treatment for color defectiveness.

Among the most prevalent diseases or conditions resulting from eye diseases identified at NTID at RIT are: (a) Strabismus (failure of the two eyes to work together properly for clear vision or depth perception because of faulty muscle control for the two eyes); (b) Rubella Retinopathy (faulty development of the receptor cells of the eyes due to German measles contracted by the mother and passed on to the fetus during pregnancy); (c) Color Defectiveness (most often an inherited trait); and (d) Retinitis Pigmentosa or RP (an inherited progressive degeneration of the retina of the eye often leading to legal blindness by the early or mid-40s).

Usher's Syndrome Also Evident

When a hearing impairment is inherited (usually severe and bilateral) and occurs in conjunction with Retinitis Pigmentosa (RP), it is often referred to as Usher's Syndrome.

Usher's Syndrome occurs in about 3 to 6 percent of all people with inherited hearing impairments.

Care must be taken in diagnosing a person as having Usher's Syndrome. RP can, and most often does, occur in the absence of hearing impairment. When it occurs together with hearing impairment and other problems such as heart deficiencies, the name of the syndrome is different.

There is no cure for either the hearing loss or the RP. Thus, there are important personal, social, academic, and career implications to consider in the treatment.

Usually the degeneration begins in the periphery or sides of the retina, causing problems with narrowing of the visual fields and decreased ability to see in dim illumination or darkness. Later, as it progresses to the more central, posterior portions of the retina, it begins to cause problems with near and far visual acuity and color vision.

People with RP often become legally blind by the early or mid-40s. Legal blindness is defined, in most states, as visual acuity reduced to 20/200 or poorer in both eyes with best correction and/or visual fields narrowed to 20° or less (a condition often referred to as tunnel vision).

Some students are not aware that they have Usher's Syndrome. And most don't realize what it can mean for them. This is why there are such tremendous implications for good visual screening, medical follow-up, counseling, and career selection and educational processes.

When Are These Visual Problems Usually Detected?

That depends on the type and nature of the visual problem. Often the functional visual problems are detected during the early school years through visual screening programs or by accident. In other cases, such as often occurs with Retinitis Pigmentosa, the problem isn't detected until later in young adulthood or the early 20s when the disease has progressed to the point where it really begins to affect functional vision. It's important to realize, however, that even significant functional visual problems and diseases may go undetected.

Why Do These Problems Go Undetected?

Many students don't realize they need visual attention because of lack of appropriate or no visual screening and follow-up programs in their schools. Others will have inappropriate corrective lenses because of poor communication during their ophthalmological or optometric examination.

Only in the past 10 years have persons working with hearing-impaired people begun to be aware of the inordinately high incidence of visual impairments among deaf and hard-of-hearing people. Many people, including the families of hearing-impaired persons, still don't know about this potential problem.

Possible Solutions

Studies show that implementation of the following recommendations are important if visual impairments among hearing-impaired people are to be identified as early as possible so that these people may make optimum use of their vision:

1. A thorough eye examination should be performed for all persons upon discovery of a hearing loss.

2. All persons with severe to profound hearing loss should receive periodic hearing and visual examinations.

3. Interpreters skilled in signing and fingerspelling should be used, as appropriate, to ensure adequate communication during visual screening tests and eye examinations of hearing-impaired persons.

4. In addition, Drs. Johnson and Caccamise recommend that all persons working with hearing-impaired people should receive training related to optimizing the use of vision by all hearing-impaired people — including teachers, therapists, and hearing-impaired persons' families.

More Information:
Dr. Donald Johnson (716) 475-6434,
Dr. Frank Caccamise (716) 475-6420, or
Susan Brannen (716) 475-6554.

Who We Are

NTID at RIT is the world's largest technological college for the deaf. Created by Congress and funded by the U.S. Department of Education, it represents the world's first effort to educate large numbers of deaf students within a college campus planned primarily for hearing students. Together with 15,000 full and part-time hearing students, nearly 1,250 college-age deaf students from all 50 states and Puerto Rico study and reside on the campus of Rochester Institute of Technology.

In addition to the academic programs based within NTID, RIT's deaf students also benefit from nearly 200 other technical and professional courses of study offered by RIT's other eight colleges.

NTID at RIT offers deaf students the opportunity to go to school in a hearing environment and thus make their transition to a hearing society easier and more effective.

Editor's Note:

Feel free to use as much of this copy as you like. And would you please send us a clipping to show how you used it? Send to Public Information Office/NB, NTID, Rochester Institute of Technology, P.O. Box 9887, Rochester, NY 14623. Thanks.

Rochester Institute of Technology
National Technical Institute for the Deaf

One Lomb Memorial Drive
Post Office Box 9887
Rochester, New York 14623

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DOWN'S SYNDROME

Definition

Down's Syndrome is the most common and readily identifiable genetic condition associated with mental retardation. It is caused by chromosomal abnormality: for some unexplained reason and due to no one's fault, an accident in cell development results in 24 instead of the usual 23 chromosomes. This extra gene material changes the orderly development of body and brain.

Prevalence

Approximately 7,000 children with Down's Syndrome are born in the U.S. each year, about 1 per 800 live births. Although parents of any age may have a Down's Syndrome child, the incidence is higher for children born to women and men over 35. Most common forms of the Syndrome do not usually occur more than once in a family.

Characteristics

There are over 50 clinical signs of Down's Syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- poor muscle tone
- slanting eyes with folds of skin at the inner corners (called epicanthic folds)
- white ("Brushfield") spots in the iris of the eye
- transverse crease on the palm
- flat bridge of nose
- short neck
- small head
- small mouth
- heart disorders in approximately 40% of people with Down's Syndrome
- a tendency to respiratory infections

Educational Implications

Intervention and stimulation programs can begin early in the child's life, shortly after a diagnosis of Down's Syndrome has been confirmed. Children with Down's Syndrome develop in different ways and at different paces. Their level of retardation may range from medium to severe. Although it is impossible to predict future school achievement, early attention to motor, communication, thinking, and self care skills is important for the child's later functioning and for the family's well-being.

The same general principles of instruction for any child with retarded development apply to a child with Down's Syndrome. They include:

- emphasis on concrete rather than abstract materials,
- prompt and systematic feedback, and
- sequential progression in small steps with periodic reviews.

Frequently, children with Down's Syndrome must be helped to learn everyday tasks that nonhandicapped children learn incidentally.

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Resources

Association for Children with Down's Syndrome
2616 Martin Avenue
Bellmore, NY 11710

Association for Retarded Citizens
2501 Avenue J
Arlington, TX 76011

Caring
P.O. Box 196
Milton, WA 98354

Down's Syndrome Congress
1640 W. Roosevelt Road, Room 156-E
Chicago, IL 60608

National Association for Down's Syndrome
P.O. Box 63
Oakland, IL 60303

National Down's Syndrome Society
146 East 57th Street
New York, NY 10022

(National Down Syndrome Society in New York has a toll free hotline: 800-221-4602 NY only: 212-764-3070)

Parents of Down's Syndrome Children
11507 Yates Street
Silver Spring, MD 20902

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EMOTIONAL DISTURBANCES

Definitions

Many terms are used to denote severe behavior problems (emotional handicaps or disturbances, behavior disorders, psychological disorders, social maladjustment, delinquency, schizophrenia, mental illness, and psychosis). However, most people would agree that each of these terms indicates behavior that is significantly different from what is expected of someone at a particular age.

Public Law 94-142, The Education for All Handicapped Children Act, defines serious emotional disturbance as "a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

- an inability to learn which cannot be explained by intellectual, sensory, or health factors;
- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- inappropriate types of behavior or feelings under normal circumstances;
- a general pervasive mood of unhappiness or depression;
- a tendency to develop physical symptoms or fears associated with personal or school problems." (U.S. Federal Register, 42, August 23, 1977, pp. 42478-42479).

The Federal definition further points out that the term includes children who are schizophrenic, but not children who are socially maladjusted, unless they are seriously emotionally disturbed.

Whatever the definition, an educational viewpoint stresses that the socially unacceptable or personally unsatisfying patterns of children can be changed with the appropriate intervention approach.

Prevalence

The number of children and youth under 18 with serious emotional/behavioral problems is estimated at approximately 50,000, or 2% - 10% of the total school age population. The lower range reflects the most severe emotional/behavioral problems.

Characteristics

The literature suggests that children and youth with emotional/behavioral disorders exhibit a variety of patterns, including:

- acting out
- withdrawal
- excessive fear or anxiety
- immaturity
- poor coping skills
- delinquency
- hyperactivity
- attention problems
- sub-par academic achievement
- impulsivity

The list must not be taken too literally, however. Most people can be said to exhibit the above characteristics at various times of their lives. Such a pattern may denote a severe problem whem it persists over a long period of time, recurs frequently, or jeopardizes the child's or other people's health and safety.

Educational Implications

In the past, the prevailing approach with emotional/behavior disorders was based in psychiatry. Recently, however, educational approaches have come to the forefront, especially those which emphasize prevention and early detection. In many cases, teachers can get extra support and maintain the student in the regular classroom. The trend towards less specialized placement has greatly affected residential schools and special schools for children with emotional/behavioral problems. Many of these programs are moving towards intensive, short term intervention.

Behavior modification is one of many ways to reduce children's inappropriate behavior and encourage desired behavior. Whatever the approach, it is important that teachers and parents react as consistently as possible. Many approaches to child management now stress the child's role in controlling his or her own behavior, leading to greater self awareness and independence.

Support and related services staff makes a vital contribution to the education of children with behavior/emotional problems. Effective teaching may draw on a variety of other disciplines and theoretical approaches, including art and music therapy, group process, and dramatics.

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Resources

American Association of Psychiatric Services for Children
1522 K Street, NW
Suite 1112
Washington, DC 20005

Council for Children with Behavior Disorders
c/o Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Mental Health Association
1800 North Kent Street
Arlington, VA 22209

National Alliance for the Mentally Ill
1234 Massachusetts Avenue, NW
Suite 721
Washington, DC 20005

National Clearinghouse for Mental Health Information
National Institute of Mental Health, HHS
15C-17 Parklawn Building
5600 Fishers Lane
Rockville, MD 20857

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EPILEPSY

DEFINITION

According to the Epilepsy Foundation of America, epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working properly, a persons consciousness, movement, or actions may be altered for a short time. These physical changes are called epileptic seizures. Epilepsy is therefore sometimes called a seizure disorder. Epilepsy affects people in all nations and of all races.

Some people can experience a seizure and not have epilepsy. For example, many children have convulsions from fevers, these febrile convulsions are one type of seizure. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. A single seizure does not mean the person has epilepsy.

PREVALANCE

About 2.5 million Americans have epilepsy. Of the 100,000 new cases that develop each year, three quarters of them are in children and adolescents.

CHARACTERISTICS

Although the symptoms listed below are not necessarily indicators of epilepsy, it is wise to consult a doctor if you or a member of your family experiences one or more of them:

- "Blackouts" or periods of confused memory,
- Episodes of staring or unexplained periods of unresponsiveness;
- Involuntary movements of arms and legs;
- "Fainting spells" with incontinence or followed by excessive fatigue;
- Odd sounds, distorted perceptions, episodic feelings of fear that cannot be explained.

Seizures can be generalized, meaning that all the brain cells are involved. One type of generalized seizure consists of a convulsion with a complete loss of consciousness. Another type looks like a brief period of fixed staring.

Seizures are partial if the brain cells not working properly, are limited to one part of the brain. Partial seizures may produce periods of automatic behavior and altered consciousness.

EDUCATIONAL IMPLICATIONS

Epilepsy is defined as one of the potentially handicapping conditions in P.L. 94-142, The Education for All Handicapped Children Act. A student with epilepsy doesn't necessarily require a special education placement unless he or she also has some other special need such as a learning disability or mental retardation.In these instances, the epilepsy or related conditions may then interfere with the child's ability to learn.

If a child's physical or intellectual skills seem markedly altered since the seizures began, tell your doctor. There may be an associated hearing or perception problem caused by brain changes. In addition, if a child has the type of seizure characterized by a brief period of fixed staring at school, he/she may be missing parts of what the teacher is saying. Ask your child's teacher to observe and document these episodes.

It's important that teachers understand about the child's condition, possible effects of medication, and what to do in case a seizure occurs at school. Most parents find that a friendly conversation with the teacher(s) at the beginning of the school year is the best way to handle the situation. Even if a child has seizures that are largely controlled by medication, it is still best to notify the school staff about the condition.

Children and youth with epilepsy must deal with the psychological and social aspects of the condition; this includes its lifelong nature, uncertain occurrence, loss of self control, and negative attitudes towards the condition.

School personnel and parents should work together to monitor the effectiveness of medication as well as any side effects. Their 'written observations will be helpful to the neurologist.

Individual decisions must be made regarding a child's participation in physical activities It is most important that both parents and teachers avoid overprotection.

There are many materials available for parents and teachers, so that they can understand how to work most effectively together. The student will benefit the most when both teachers and parents are working together.

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RESOURCES

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700

Epilepsy Information Line
University of Washington-Seattle
Toll Free Information Line:
(800) 426-0660
(206) 323-8174 (WA Only)

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LEARNING DISABILITIES

DEFINITION

The regulations for Public Law 94-142 (The Education for All Handicapped Children Act) define a learning disability as "disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations."

The Federal definition further states that learning disabilities include "such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." According to the law, learning disabilities does not include learning problems that are primarily the result of visual, hearing, or motor handicaps; mental retardation; or environmental, cultural, or economic disadvantage. Definitions of learning disabilities also vary among states.

Having a single term to describe this category of children with handicaps reduces some of the confusion, but there are many conflicting theories about what causes learning disabilities, how many children with learning disabilities there are, and so on. The label "Learning Disabilities" is all-embracing; it describes a syndrome, not a specific child with specific problems. The definition is comprehensive; it assists in classifying children, not teaching them. Parents and teachers need to concentrate on the individual child. They need to observe both how and how well the child performs, to assess strengths and weaknesses, and to provide and invent ways to help each child learn. It is important to remember that there is a high degree of interrelationship and overlapping among the areas of learning. Therefore, learning disabled children may exhibit a combination of characteristics. These problems may mildly, moderately, or severely impair the learning process.

PREVALANCE

Many different estimates of the number of learning disabled children have appeared in the literature (ranging from 1% to 30% of the general population). Differences in estimates perhaps reflect variations in the definition. The most widely cited estimate is that 2% to 3% of school-aged children and youth are learning disabled.

CHARACTERISTICS

Students who have learning disabilities may exhibit a wide range of traits, including problems with reading comprehension, spoken language, writing, or reasoning ability. Hyperactivity, inattention, and perceptual coordination problems may also be associated with learning disabilities, but are not examples of it. Other traits that may be present include a variety of symptoms of brain dysfunction, such as uneven and unpredictable test performance, perceptual impairments, motor disorders, and such emotional characteristics as impulsiveness, low tolerance for frustration and problems in handling day to day situations.

One of the most apparent characteristics of learning disabilities is a significant difference in the child's achievement in some areas, as compared to his or her overall intelligence.

The major learning disabilities occur in four categories:

1. Spoken language: Delays, disorders, and deviations in listening and speaking.
2. Written language: Difficultites with reading, writing, and spelling.
3. Arithemetic: Difficulty in performing arithmetic functions or in comprehending basic concepts.
4. Reasoning: Difficulty in organizing and integrating thoughts.

EDUCATIONAL IMPLICATIONS

Because learning disabilities are manifested in a variety of behavior patterns, the Individual Education Program (IEP) must be designed carefully. A team approach is important for educating the child with a learning disability beginning with the IEP process and continuing with close collaboration among special class teachers, parents, resource room teachers, regular class teachers, and others.

Some teachers report that the following strategies have been effective with some students who have learning disabilities:

- High structure and clear expectations
- The use of short sentences and a simple vocabulary
- Opportunities for success in a supportive atmosphere
- Flexibility in classroom procedures (e.g., allowing the use of tape recorders for note-taking and test-taking when students have trouble with written language)
- Use of self-correcting materials that provide for immediate feedback without embarrassment.

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RESOURCES

Association for Children and Adults
with Learning Disabilites
4156 Library Road
Pittsburg, PA 15234
(412) 341-1515 or 8077

Closer Look
LD TEENLINE
800-522-3458 (Mon. thru Fri. 10 am to 4 pm)
A toll-free information and referral service
for parents of learning disabled teens,
educators and teens themselves.

Division of Learning Disabilities
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Foundation for Children With Learning
Disabilities (FCLD)
P.O. Box 2929
Grand Central Station
New York, NY 10016
(212) 687-7211

National Network of Learning Disabled
Adults (NNLDA)
808 North 82 Street #F2
Scottsdale, AZ 85257

Orton Dyslexia Society
724 York Road
Baltimore, MD 21204
(301) 296-0232

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MENTAL RETARDATION

Definition

The definition of the American Association on Mental Deficiency (1983) is widely accepted:

> Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

Significantly subaverage means a score of two or more standard deviations below the mean on an individual intelligence test. Adaptive behavior refers to the individual's adjustment to everyday life. Deficits in adaptive behavior may occur in communication skills, socialization, academic learning, and vocational competence, and will vary according to the age of the individual. The developmental period is from birth to age twenty-two.

It should be noted that the AAMD definition makes no mention of prognosis or cause, as a more medically oriented explanation might. Although there are more than 250 specific identified causes, in most cases the exact reasons for the retardation are unknown. Except for a small percentage of cases which require medical intervention, treatment and educational programming are not related to etiology, but rather to the individual's functioning level and learning styles.

Prevalence

Depending upon the definition and measurement approach used, estimates of mentally retarded persons in the general population range from 1% (when relying on the adaptive behavior measurement) to 3% (when the IQ score is emphasized).

Characteristics

Many authorities agree that mentally retarded individuals develop in the same way that nonretarded persons do, but at a slower rate, and reach a lower overall level of functioning. Others suggest that persons with retardation have difficulties in particular cognitive areas, such as attention, perception, and memory. Depending on the extent of the retardation - mild, moderate, severe, or profound - individuals will develop differently in academics, social skills, and vocational adequacy.

Educational Implications

There are several important points to consider when working with mentally retarded persons, including the importance of emphasizing concrete materials, providing prompt and consistent feedback, stressing the child's success, and proceeding in small sequential steps with frequent reviews. Other approaches stress the need for obtaining and holding the student's attention and structuring learning of simple everyday tasks that nonretarded persons learn incidentally. Similarly, tasks should be presented so that students generalize the skills to other situations. As with all education, individualization is a starting point for successful learning.

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Increasingly, mildly retarded ("educable") students participate in the regular classroom with resource support. Moderately retarded ("trainable") students are frequently served in special classes with a greater emphasis on self-help and vocational than academic skills. Students with severe and profound mental retardation frequently have additional handicaps and require instruction designed to promote basic communication and daily living skills. Career and vocational education, important parts of all children's education, become even more important for students with mental retardation.

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Turnbull, H.R., and Turnbull, A.P. Parents Speak Out: Views from the Other Side of the Two Way Mirror. 1978. (Charles E. Merrill Publishing Company, Columbus, OH 43216)

Zukerman, L. and Yura, M.T. Raising the Exceptional Child: Meeting the Everyday Challenge of the Handicapped or Retarded Child. 1979. (Hawthorn Books, 2 Park Avenue, New York, NY 10016)

Resources

American Association on Mental Deificiency
5101 Wisconsin Avenue, NW, Suite 405
Washington, DC 20016

Caring
P.O. Box 40
Milton, WA 98354

International League of Societies for the Mentally Retarded
12 Rue Forestiere
Brussels 5, Belgium

National Association for Retarded Citizens
P.O. Box 6109
2501 Avenue J
Arlington, TX 76011

People First International (self advocacy group for mentally retarded persons)
P.O. Box 12642
Salem, OR 97304

Division on Mental Retardation
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

President's Committee on Mental Retardation
U. S. Department of Health & Human Services
Office of Human Development Services
Washington, DC 20201

Special Olympics, Inc.
1701 K Street, NW, Suite 203
Washington, DC 20006

The Association for the Severely Handicapped
7010 Roosevelt Way, NE
Seattle, WA 98115

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SEVERE HANDICAPS

Definition

The term severe handicap indicates an intense degree of a condition such as mental retardation, deafness, blindness, physical disability or emotional disturbance. It may also refer to more than one, or a "multiple" handicap, such as mental retardation and cerebral palsy or blindness and physical disability.

Children and youth with severe handicaps may be functionally delayed; that is, they cannot perform basic academic and/or daily living skills.

Characteristics

Children and youth with multiple or severe handicaps may exhibit a wide range of characteristics, depending upon the combination of handicaps, the child's age, and the quality of intervention services. There are, however, some traits children with severe or multiple handicaps may share, including:

- limited speech or communication
- difficulty in basic physical mobility skills
- inability to care for themselves
- failure to relate or attend to others
- tendency toward self injury or abuse

Educational Implications

In the past, children with severe handicaps were regularly excluded from the public schools. Because of P.L. 94-142, the Education for All Handicapped Children Act, public schools are now serving large numbers of severely handicapped students. Some of these children have returned from institutions, others may be entering structured programs for the first time, and still others are graduates of high quality early intervention programs.

For these students, related services take on an increasingly important role. Speech and language therapists, physical and occupational therapists, and other specialists work closely with the classroom teacher and parents.

Frequently classroom arrangements must take into consideration students' needs for medication, self care requirements, or special equipment.

Integration with other, nonhandicapped students, is another concern. For many severely handicapped students, placement in a special class of a local school allows for interaction during the normal school day.

Vocational and leisure skills are critical considerations for children and youth with severe handicaps. Programming for maximum independence should begin early and draw on community services (including group homes, vocational programs, and recreation) to help in post-school adjustment.

References

Baker, B.L. and others. Toward Independent Living: Steps to Independence. 1980. A Skills Training Series for Children with Special Needs. (Research Press, Box 3177, Champaign, IL 61820)

Intended to help parents teach independent living skills to their moderately or severely retarded adolescents, the book focuses on self care, home care, and information skills.

Cunningham, C., Sloper, P. Helping Your Exceptional Baby: A Practical and Honest Approach to Raising a Mentally Handicapped Child. 1980. (Pantheon Books, 201 East 50th Street, New York, NY 10022)

The book describes exercises and games to stimulate development of young children with Down's Syndrome and other types of retardation.

Doyle, P.B., and others. Helping the Severely Handicapped Child. A Guide for Parents and Teachers. 1979. (Thomas Y. Crowell Publishers, 10 East 53rd Street, New York, NY 10022)

The book presents practical suggestions for helping the severely handicapped child at school and at home. There is also a section on special equipment.

Featherstone, H. A Difference in the Family: Life with a Disabled Child. 1980. (Basic Books, Inc., 10 East 53rd Street, New York, NY 10022)

The author, an educator and parent of a severely handicapped child, writes about parents' and siblings' feelings, marital stress, and both sides of the parent-professional partnership.

Finnie, N.R. Handling the Young Cerebral Palsied Child at Home. 1975. (E.P. Dutton, 2 Park Avenue. New York, NY 10016)

The book presents a practical approach (with illustrations) to feeding, dressing, and caring for the young child with cerebral palsy.

Freeman, R.D., and others. Can't Your Child Hear? A Guide for Those who Care About Deaf Children. 1981. (University Park Press, Baltimore, MD 21202)

The guide includes a section on deaf children with other disabilities.

Holland, E. Let's Try to Help: A Guide for Parents of Young Multihandicapped Children. 1976. (Oak Hill School, Connecticut Institute for the Blind, 120 Holcomb Street, Hartford, CT 06112)

Jegard, S., and others. A Comprehensive Program for Multihandicapped Children: An Illustrated Approach. 1980. National Institute on Mental Retardation, Kinsmen NIMR Building, York University, 4700 Keele Street, Downsview, Ontario, M3J 1P3)

Murray, J.B., and Murray, E. *And Say What He Is: The Life of a Special Child.* 1975. (MIT Press, 28 Carleton Street, Cambridge, MA 02142)

Parents of a severely handicapped child describe their encounters with the medical profession, educators, relatives, and friends.

Sailor, W., Wilcox, B., and Brown, L. (Eds.) *Methods of Instruction with Severely Handicapped Students.* 1980. (Paul H. Brookes Publishers, P. O. Box 10624, Baltimore, MD 21204)

The book offers guidelines for the education of students with severe disabilities.

Scott, E.P. and others. *Can't Your Child See?* 1977. (University Park Press, Baltimore, MD 21202, 1977)

Written for parents of visually handicapped children, the book includes a section on the needs of multiply handicapped blind children.

Sontag, E., Smith, J., and Certo, N. (Eds.) *Educational Programming for the Severely and Profoundly Handicapped.* 1977. (Council for Exceptional Children, Division on Mental Retardation)

The book includes sections on such topics as family involvement, services to rural areas, infant programs, and teaching strategies.

Van Etten, G., Arkell, C., and Van Etten, C. *The Severely and Profoundly Handicapped. Programs, Methods, and Materials.* 1980. (C.V. Mosby Company, 11830 Westline Industrial Drive, St. Louis, MO 63141)

Sections on diagnosis, curriculum, materials and equipment are included in this text on education considerations.

Walsh, S.R., Holzberg, R. (Eds.) *Understanding and Educating the Deaf/Blind Severely and Profoundly Handicapped.* 1979. (Charles C. Thomas Publishers, 2600 S. First Street, Springfield, IL 62717)

Resources

Alexander Graham Bell Association for the Deaf
3417 Volta Place, NW
Washington, DC 20007

The Association is devoted to providing hearing impaired people with the opportunity to develop and use speech. AGB provides information and publishes a newsletter.

American Coalition of Citizens with Disabilities
1200 15th Street, NW
Washington, DC 20036

ACCD is a national organization with state and local chapters that promote equal opportunities and civil rights for people with disabilities. Members receive a monthly newsletter.

American Council for the Blind
Suite 506
1211 Connecticut Avenue, NW
Washington, DC 20036

ACB operates 15 special interest groups including parents of visually impaired children, visually impaired parents, and guide dog users. The Council provides information about aides and legal rights.

American Foundation for the Blind
15 West 16th Street
New York, NY 10011

Established to help people acquire rehabilitation, education and employment services, the Foundation manufactures (or adapts) hundreds of aids and appliances, publishes journals and newsletters, and maintains an extensive library.

Association for Retarded Citizens, National Headquarters
P. O. Box 6109
2501 Avenue J
Arlington, TX 76011

ARC and its state and local chapters promote better education, training, job opportunities, and housing for mentally retarded children and adults. ARC also publishes a newsletter, THE ARC.

Avenues
c/o Mary Ann Schmidt
5430 East Harbor Heights Drive
Port Orchard, WA 98366

Avenues is a support group for children and adults with Arthrogryposis Multiplex Congenita. Avenues publishes a twice yearly newsletter.

Cornelia De Lange Syndrome Foundation
60 Dyer Avenue
Collinsville, CT 06022

The Foundation publishes a newsletter and directory for parents and children with the syndrome.

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

CEC is a membership organization dedicated to advancing the education of exceptional children and youth. CEC produces publications on special education topics and also conducts computer searches of the literature.

Down's Syndrome Congress
1640 W. Roosevelt Road
Chicago, IL 60608

Composed of parents and professionals concerned with Down's Syndrome, the Congress produces a newsletter and holds an annual convention.

Epilepsy Foundation of America
4351 Garden City Drive, Suite 406
Landover, MD 20785

Through its 100 local affiliates and 60 local information and referral centers, EFA provides advocacy and services for people with epilepsy.

Friedreich's Ataxia Group in America
P. O. Box 11116
Oakland, CA 94611

The organization publishes a newsletter and brochure.

Goodwill Industries of America
9200 Wisconsin Avenue, NW
Bethesda, MD 20814

Goodwill Industries provides job training, testing, physical and speech therapy, counseling and competitive job placement for people with mental and physical handicaps. Over 175 local groups offer a wide variety of services, including summer camps, day nurseries or adapted housing. Information and newsletters are also offered.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605

The goal of the March of Dimes Birth Defects Foundation is prevention. The Foundation supports medical research, sponsors medical services and community services, and acts as an information clearinghouse.

National Ataxia Foundation
6681 Country Club Drive
Minneapolis, MN 55427

Ten chapters of the Foundation offer genetic counseling and moral support, make referrals to medical and other direct service providers, and raise funds for research. They also provide information on hereditary tremor, and Friedreich's ataxia.

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910

NAD is a consumer organization that promotes legislation and provides information on programs and services for deaf people of all ages.

National Association of Deaf-Blind
2703 Forest Oak Circle
Norman, OK 73071

An advocacy organization founded by parents to further educational, rehabilitation, and employment opportunities for deaf-blind people, the Association provides information and publishes a newsletter.

National Easter Seal Society
2023 W. Ogden Avenue
Chicago, IL 60612

In addition to producing a large number of publications on disabilities, the National Easter Seal Society sponsors clinics, research, and workshops.

National Neurofibromatosis Foundation
70 West 40th Street, 4th Floor
New York, NY 10018

The Foundation's activities include public awareness campaigns and professional workshops. Publications and referral services are also offered.

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, NW
Washington, DC 20005

NSAC is an organization of parents and professionals involved in legislation, education and research to benefit people with severe communication and behavior disorders.

National Spinal Cord Injury Association
369 Elliot Street
Newton Upper Falls, MA 02164

The Association works through chapters to develop quality care for paraplegics and quadiplegics. Some chapters offer direct care services.

National Tuberous Sclerosis Association, Inc.
P. O. Box 159
Laguna Beach, CA 92652

The Association offers counseling, referral, information, and support services to families and physicians.

Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, MN 55436

The Association provides information and referral to parents and professionals.

Spina Bifida Association of America
343 S. Dearborn Street
Suite 319
Chicago, IL 60604

The SBAA emphasizes local parent and patient support groups, of which there are approximately 100 in the U.S. and Canada. The Association publishes manuals and booklets for parents and teachers.

The Association for the Severely Handicapped (TASH)
7010 Roosevelt Way, NE
Seattle, WA 98115

TASH members include educators, therapists, researchers, doctors, parents, and others concerned with severely handicapped children and adults. TASH publications include newsletters, journals, and books.

Tourette Syndrome Association
Bell Plaza Building
41-02 Bell Boulevard
Bayside, NY 11361

This organization offers information and support through more than 80 chapters in the U.S., Canada, and England. The organization publishes a newsletter and maintains a referral file of physicians.

United Cerebral Palsy Associations
66 East 34th Street
New York, NY 10016

UCPA and its affiliates 1) fund research; 2) advocate for the civil rights of disabled people; 3) provide public education programs which emphasize prevention; and 4) provide direct services including medical services, special education, recreation, counseling and adapted housing.

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SPEECH AND LANGUAGE IMPAIRMENTS

Definitions

Speech and language impairments refer to problems in communication. Examples include fluency problems (called dysfluency or commonly, "stuttering"), articulation problems, voice disorders, and aphasia (a difficulty using words, usually as a result of brain injury).

The development of speech and/or language may be delayed due to many factors, including environment or hearing loss. Sometimes speech or language impairments may result from other conditions, such as learning disabilities, mental retardation, and cerebral palsy.

Prevalence

Five percent of school aged children are estimated to have speech and language disorders. The number of students identified with delayed speech decreases steadily as children mature.

Characteristics

A child with delayed communication is noticeably behind his or her agemates. Frequently a child will have greater receptive (understanding) than expressive (speaking) language skills.

In that case, children may be able to follow directions but have problems producing comprehensible speech or correct syntax and articulation.

Students whose primary language is different from standard English may have difficulty communicating in the majority language.

Stuttering, a disorder of speech flow, most often appears between ages 3 and 4 and may progress from a periodic to a chronic problem. Although many children who stutter recover by puberty or early adolescence, speech and language therapy should be considered.

Physical problems, such as cleft lip or palate, may result in difficulties with certain sounds or with control of the voice quality. Articulation problems, a very common form of speech disorder, result in omissions, substitutions, or distortions of sounds.

Typical voice disorders include hoarseness, breathiness, or sudden breaks in loudness or pitch. Frequently, voice disorders are combined with other speech problems to form a complex communication disorder.

Educational Implications

Language experiences are central to a young child's development. Because they introduce and interpret the world to their children via language, parents play a crucial role in stimulating interest and skills with words.

Speech and language therapists function in a support role for teachers of children with communication handicaps. Sometimes therapists remove a child from the class for individual speech therapy, although many therapists now consult with teachers about the best ways to help the child in the regular class setting. The same kinds of helpful techniques may be shared with the parents, so the improvement approach is consistent at home and at school.

Technology can help children whose physical conditions make communication difficult. The use of electronic communication devices allows even severely physically disabled people to engage in the give and take of shared thought.

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Bloodstein, O. A Handbook on Stuttering. 1975. (Easter Seal Society, 2023 W. Ogden Avenue, Chicago, IL 60612)

Hixon, T.J., Shribers, L.D., and Saxman, J.H. (Eds.) Introduction to Communication Disorders. 1980. (Prentice-Hall, Inc., Englewood Cliffs, NJ 07632

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Van Hattum, R.J. Communication Disorders. An Introduction. 1980. (Macmillan Publishing Company, Inc., 866 Third Avenue, New York, NY 10022)

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Wiig, E.H. Talkabout: Developing Prosocial Communication Skills. 1982. (Charles E. Merrill Publishing Co., Columbus, OH 43216)

Resources

American Cleft Palate Educational Foundation
Parent Liaison Committee
Louisiana State University Medical Center
Department of Audiology and Speech Pathology
3735 Blair
Shreveport, LA 71103

American Speech Language and Hearing Association
10801 Rockville Pike
Rockville, MD 20852

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234

Division for Children with Communication Disorders
c/o The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Institute of Neurological and Communicative Disorders and Stroke
National Institutes of Health, HHS
Building 31, Room 8A--06
Bethesda, MD 20205

Prescription Parents (Cleft Lip/Palate)
P. O. Box 426
Quincy, MA 02269

Trace Research and Development Center for the Severely Communicatively Handicapped
314 Waisman Center
1500 Highland Avenue
Madison, WI 53706

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SPINA BIFIDA

Definitions

Spina bifida means cleft spine, which is an incomplete closure in the spinal column. The three types of spina bifida (from mild to severe) are:

1. SPINA BIFIDA OCCULTA: There is an opening in one or more of the vertebrae (bones) of the spinal column without damage to spinal cord.
2. MENINGOCELE: The meninges, or protective covering around the spinal cord, have pushed out through the opening in the vertebrae in a sac called the "meningocele". However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.
3. MYELOMENINGOCELE: Not only are there openings in vertebrae, but the spinal cord itself does not close. It usually protrudes from the back.

Prevalence

Approximately 40% of all Americans have spina bifida occulta, but very few of them ever even know it. The two other forms, collectively referred to as "spina bifida manifesta", occur in approximately one out of every thousand births. Of these, 4% have the meningocele form and 96% have myelomeningocele.

Characteristics

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the cleft, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, since the spinal cord is the system by which fluid is normally drained from the brain, the fluid may build up and cause hydrocephalus or accumulation of fluid on the brain. 70-90% of the children born with Spina Bifida have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called "shunting" which relieves the fluid buildup in the brain area. Hydrocephalus may occur without Spina Bifida, but the two defects often occur together. If a drain (shunt) is not implanted, the pressure buildup can impair the functioning of the brain.

Educational Implications

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to close the spine can be performed in the first 48 hours of life, children with spina bifida are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be planned with this consideration in mind.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of fluids. Catheterization in the schools has been an issue in the courts of some states. Where this issue has been litigated, the courts have held that clean, intermittent catheterization is a related service when it is necessary to help the child benefit from and have access to special education and related services.

Often children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressive and receptive language, reading and math. Early intervention with children who experience learning problems can make it possible to be integrated with their non-disabled peers when they begin school.

Successful integration of a child with spina bifida into a school attended by non-disabled young people sometimes requires changes in school equipment or curriculum. In the same way as a student placement should be the least restrictive one appropriate for him or her, the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the child with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving Federal funds make their programs accessible. This could mean structural changes (for example, adding elevators or ramps) or schedule or location changes (for example, offering a course on the ground floor). Recent legislation provides up to $40 million in Federal funds throughout the nation for renovation of school buildings to make them accessible.

Children with spina bifida need to learn mobility skills, often with the aid of crutches, braces, or wheelchairs. It is important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound affects on children's emotional and social development. To promote growth, parents and teachers should avoid overprotection and encourage children to take risks within the limits of safety and health. Teachers and classmates should also understand that, although children with spina bifida are physically handicapped, they are more like their classmates than different from them.

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McLone, D. Introduction to Spina Bifida. (Spina Bifida Association of America, 343 South Dearborn Street, Chicago, IL 60604, $1.50 prepaid)

Mullins, J.B. A Teacher's Guide to Management of Physically Handicapped Students. (Charles C. Thomas Publisher, 301-327 East Lawrence Avenue, Springfield IL 62717)

Nakos, E. and Taylor, S. Early Development of the Child with Myelomeningocele: A Parent Guide . 1977. (Children's Hospital Medical Center, Elland and Bethesda Avenues, Cincinnati, OH 45229, $2.75 prepaid)

Pence, B. and Nelson G. You are Special-You're The One. (Spina Bifida Association of America, 343 South Dearborn Street, Chicago, Illinois 60604, $1.50)

Pieper, E. Beyond The Family and the Institution: Residential Issues For Today. 1979. (Spina Bifida Association of America, 343 South Dearborn Avenue, Suite 317, Chicago, IL 60604, $1.50).

Pieper, E. By, For and with Young Adults with Spina Bifida. 1979. (Spina Bifida Association of America, 343 South Dearborn Avenue, Suite 317, Chicago, IL 60604, $1.50 prepaid)

Pieper, E. When Something Is Wrong with Your Body--Looking In & Reaching Out. 1977. (Spina Bifida Association of America, 343 South Dearborn Avenue, Suite 317, Chicago, IL 60604, $1.50)

Pieper, E. Sticks and Stones: The Story of a Loving Child. 1977. (Human Policy Press, P.O. Box 127, Syracuse, NY 13210, $4.00 plus $1.50 postage and handling.)

Pieper, E. Straight Talk-Parent to Parent. (Spina Bifida Association of America, 343 South Dearborn Avenue, Suite 317, Chicago, IL 60604, $1.50 prepaid)

Pieper, E. The Teacher and the Child with Spina Bifida. 1977. (Spina Bifida Association of America, 343 South Dearborn Avenue, Suite 317, Chicago, IL 60604, $1.50 prepaid)

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Swinyard, C.A. The Child With Spina Bifida. 1980. (Spina Bifida Association of America, 343 South Dearborn Ave., Suite 317, Chicago, IL 60604, $1.50 prepaid) (Available in Spanish)

Umbreit, J. & Cardullas, P. (eds.) Educating the Severely Physically Handicapped. (Special Press, P.O. Box 2524, Columbus, OH 43216)

Resources

Information on Spina Bifida

Spina Bifida Association of America
343 South Dearborn Avenue, Suite 317
Chicago, IL 60604
(312) 663-1562
(800) 621-3141 (except Illinois)

March of Dimes Birth Defects Foundation
Post Office Box 2000
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
(312) 243-8400

National Center for Education in Child and Maternal Health
3520 Prospect Street, N.W.
Washington, DC 20007

Information on Special Education

ERIC Clearinghouse on the Handicapped and Gifted
1920 Association Drive
Reston, VA 22091
(703) 620-3600

Information on Equipment for Children With Disabilities

ABELDATA
National Rehabilitation Information Center
4407 Eighth Street, N.E.
Washington, DC 20017
(202) 635-6090

Accent on Information
Post Office Box 700
Gillum Road and High Drive
Bloomington, IL 61701

Information of Design of Accessible Facilities

National Center for a Barrier Free Environment
1015 - 15th Street, N.W.
Washington, DC 20036
(202) 466-6896

Adaptive Environment Center
Massachusetts College of Arts
26 Overland Street
Boston, MA 02215
(617) 266-2666

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VISUAL IMPAIRMENTS

DEFINITIONS

The terms " legally blind", "partially sighted", and "low vision" may mean different things in legal and educational contexts. The educational definitions of the terms are given below:

- Visual handicap indicates that some type of visual problem has resulted in a need for special education.
- Blindness refers to a condition with no vision or only minimal vision (light perception). Blind students learn via Braille or other non-visual media.
- Low vision refers to limited distance vision. People with low vision are able to see items close to them. They use a combination of a vision and other senses to learn, although they may require adaptations in the lighting or size of print.

Visual impairments can include myopia, hyperopia, and astigmatism; problems in the visual field; and muscular problems that result in visual disturbances.

PREVALENCE

The rate at which visual impairments occur in the general population increases considerably with age, especially after 65. For individuals under 45, the estimated prevalence is 7 per 1,000; for individuals over 65, it is 44.5 per 1,000.

CHARACTERISTICS

The effect of visual problems on a child's development depends on the severity, type of loss, age at which the condition appeared, and overall functioning level of the child. The child may be delayed in motor, cognitive, and/or social development.

A young child with visual handicaps has little reason to explore interesting objects in the environment, and thus may miss opportunitites to have experiences and to learn. This lack of exploration may continue until hearing becomes motivating or until intervention begins.

Because the child cannot see parents or peers, he or she may be unable to imitate social behavior or understand nonverbal cues. Visual handicaps can create obstacles to a growing child's independence.

EDUCATIONAL IMPLICATIONS

The student with visual impairments should be tested early in order to assess remaining vision. Mainstreaming has been a successful way of serving the academically oriented student with visual handicaps. These students may need additional help with special equipment and modifications in the regular curriculum to emphasize listening skills, communication, orientation and mobility, vocation/career and daily living skills. Students with low or limited vision may need help in using their residual vision more efficiently and in working with special aids and materials. Students who have visual handicaps combined with other types of handicaps may have greater need for an interdisciplinary approach and may require greater emphasis on self care and daily living skills.

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Resources

American Association of Workers
for the Blind
206 North Washington Street
Alexandria, VA 22314

American Council for the Blind
1211 Connecticut Avenue, N.W.
Washington, DC 20036
(800) 424-8666-toll free
(202) 833-1251

American Foundation of the Blind
15 West 16th Street
New York, NY 10011
(212) 620-2000

American Printing House for the Blind
1800 Frankfort Avenue
Louisville, KY 40206
(502) 895-2405

Association for Education of the
Visually Handicapped, Inc.
206 N. Washington Street
Alexandria, VA 22314
(703) 836-6060

Division for the Visually Handicapped
c/o The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

International Institute for
Visually Impaired, 0-7, Inc.
1975 Rutgers Circle
East Lansing, MI 48823
(517) 351-6300
or
14 Gay Street
Newtonville, MA 02160
(617) 527-0476

National Association for Parents
of the Visually Impaired, Inc.
2011 Hardy Circle
Austin, TX 78757

National Association for the
Visually Handicapped
305 East 24th Street, 17-C
New York, NY 10010
(212) 889-3141

National Eye Institute
National Institutes of Health
Building 31, Room 6A32
Bethesda, MD 20205
(301) 496-5248

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(301) 659-9314

National Library Service
Division for the Blind and
Physically Handicapped
Library of Congress
1291 Taylor Street, N.W.
Washington, DC 20542
(202) 287-5100

National Retinitis Pigmentosa
Foundation
8331 Mindale Circle
Baltimore, MD 21207
(301) 655-1011
(301) 655-1190 (TTD)
(800) 638-2300

National Society to
Prevent Blindness
89 Madison Avenue
New York, NY 10016
(212) 684-3505

Recording for the Blind, Inc.
20 Roszel Road
Princeton, NJ 08540
(609) 452-0606

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PHYSICAL DISABILITIES AND SPECIAL HEALTH PROBLEMS

Definitions

Orthopedic or physical disabilities describe medical or structural conditions which may be serious enough to disrupt the child's development and require special attention in school. Typical examples of orthopedic or physical problems include disabilities present at birth (such as missing limbs, spina bifida, etc.), as well as physical problems resulting from other causes (such as contractures caused by burns or fractures, etc.). In addition, neurological problems, such as cerebral palsy, may be included in this category.

Health impairments may result in limited strength, vitality and/or alertness. Asthma, cardiac conditions, sickle cell anemia, epilepsy, and leukemia are examples of health impairments that could interfere with a child's education.

Prevalence

One half of one percent (.5%) is the figure usually cited in estimates of school aged children with physical or health impairments. Cerebral palsy accounts for a large part of this percentage, followed by spina bifida.

Characteristics

Physical disabilities can produce a variety of characteristics. Children may experience a wide range of restrictions on their activity, from little or none to a complete restructuring of daily life. The most severely affected children may require intensive medical and educational help.

Physical problems may interfere with children's motor functioning, communication, learning skills, or social development.

Educational Implications

The contributions of such related services as physical, occupational, and speech and language therapy are often central to the education of children with physical disabilities. The greatest progress is achieved when therapy suggestions are consistently applied in the child's home as well as in school. This carryover strengthens appropriate feeding, positioning, and language stimulation patterns.

Architectural factors must be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving Federal funds make their programs accessible. This could mean structural changes (for example, adding elevators or ramps) or schedule or location changes (for example, offering a course on the ground floor.

Sometimes the nature of the child's disability requires changes in school equipment or curriculum. In the same way as a student's placement should be the least restrictive one appropriate for him or her, the day-to-day school pattern also should be as "normal" as possible.

Physical disabilities can have profound effects on children's emotional and social development. To promote growth, parents and teachers should avoid overprotection and encourage children to take risks within limits of safety and health.

Technology holds great promise for making the life of a child with a disability more "normal." Computerized devices, for example, can help nonvocal, severely physically involved children communicate, perhaps for the first time.

Students who require recurring or longterm hospital care for their condition may need special services such as tutoring or homebound instruction to keep up with their class. Depending upon the nature and severity of the condition, counseling for the entire family may be helpful.

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Resources

Accent on Information
P. O. Box 700
Gillum Road and High Drive
Bloomington, IN 61701

American National Standards Institute
1430 Broadway
New York, NY 10018
(212) 354-3300

American Coalition of Citizens with Disabilities
1346 Connecticut Avenue, NW
Washington, DC 20036
(202) 785-4265

Cancer Information Clearinghouse
National Cancer Institute
Bethesda, MD 20205
(301) 496-4070

The Candlelighters Foundation
2025 I Street, NW - Suite 1011
Washington, DC 20006
(202) 659-5136

Division on Physically Handicapped
c/o The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700

March of Dimes Birth Defects Foundation
P. O. Box 2000
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

National Association of the Physically Handicapped
76 Elm Street
London, OH 43140
(614) 852-1664

National Center for Barrier Free Environment
1015 15th Street, NW
Washington, DC 20005

National Easter Seal Society
2023 W. Ogden Avenue
Chicago, IL 60612
(312) 243-8400

National Library Service for the Blind
and Physically Handicapped
Library of Congress
1291 Taylor Street, NW
Washington, DC 20547

National Rehabilitation Information Center
4407 Eighth Street, NW
Washington, DC 20017

United Cerebral Palsy Association
66 E. 34th Street
New York, NY 10016
(212) 481-6300

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Information from the National Information Center for Handicapped Children and Youth

January, 1984

Work and the Severely Handicapped
The Transition for Youth

IT IS SOMETIMES ARGUED that vocational preparation is not appropriate for persons who have severe handicaps because few of them may ever attain complete independence. However, our society places great value on work and on the desirability of working. If certain individuals are denied the option of performing work, they are denied a basic opportunity to participate in normal life. The work experience is part of the process of normalization for all handicapped people.

Moreover, when severely handicapped people are working, all of them are contributing to society, and many of them are earning wages, paying taxes, and reducing the Federal, State, and local revenues that might otherwise be spent for their maintenance.

Overall Employment Trends

Overall youth unemployment has become a major labor problem in the United States, as well as in other countries. A major proportion of the approximately 20,000 to 30,000 young severely handicapped persons who leave public special education programs each year face even fewer opportunities for reducing their dependence on others through work. Madeleine Will, Assistant Secretary for the Office of Special Education and Rehabilitative Services estimates that between 50 and 75 percent of working-age disabled people are unemployed, and noted in a recent speech to members of The Association for the Severely Handicapped that "educational and vocational services designed to lead to employment are often unavailable or oversubscribed."

The Changing Scene

When we speak of severe handicaps, we speak of severe mental retardation, severe emotional disturbance or autism, some neurological or crippling conditions, and some multiple handicaps (such as deafness and blindness occurring in the same individual). Many people with severe handicaps were formerly almost universally sent to state institutions — until the 1970's when laws such as the Rehabilitation Act of 1973 and Public Law 94-142 (The Education of All Handicapped Children Act of 1975) provided for their education and training in the least restrictive environment of their communities. Developmental disabilities legislation (the Developmental Disabilities Act of 1975, for instance) also provided an impetus for community support and more independence for individuals with severe handicaps.

This transition of severely handicapped individuals from State hospitals to public schools and community programs is still taking place. Meanwhile, many cities and counties have not yet been able to organize the educational, vocational, and life skills programs that can make it possible for severely handicapped youth and adults to succeed in their own home towns.

One side of the coin is changing the environment, or establishing independent living centers that identify and coordinate services, or develop them if they are not available. To achieve their greatest degree of independence, severely handicapped individuals may need such services as housing, attendant care, transportation, information and referral concerning goods and services, counseling, advocacy, training in independent living, maintenance and repair of equipment, and social and recreational services.

The other side of the coin is "changing the person," or providing the instruction and experiences that will help the severely handicapped person to gain vocational and life skills.

The Ability to Learn

Expectations about the learning abilities of severely handicapped people have risen in the past decade. Recent attention to developing their skills has had encouraging results. Research consistently shows that these people can learn to perform a variety of vocational and independent living tasks if they receive proper training. It has also been found that traditional intelligence tests, tests of manual skill, and work sample tests do not accurately predict the success that severely handicapped workers can actually achieve on the job.

Severely handicapped trainees do best when their instruction is tailored to their particular styles of learning, which vary from person to person. One method of instruction (task analysis) divides a larger task into many smaller parts which trainees learn, one by one, until they can gradually link them all together to master the entire procedure. Severely handicapped people make these gains slowly, but they can make them with accuracy and with skill.

These individuals also benefit from positive reinforcement, or a reward for correct performance while they are learning new tasks. Early in training, items or activities that trainees enjoy may be suitable reinforcements. Later on, these rewards are gradually replaced with the kinds of reinforcements that regularly occur in the work place.

Many people with severe handicaps do not automatically imitate other people. Therefore, their instructors model (or show them) the proper way to perform a task, over and over, and help them to repeat it until they have mastered it. Trainees also need repeated practice in performing tasks under various conditions and in various places, so that they will later transfer what they have learned into the employment setting. Role playing, rehearsals of job behavior, and gradual on-the-job training help trainees to make this transfer.

In addition to developing work skills, severely handicapped individuals often need training in appropriate social and employment behaviors. Many educators believe that the emphasis of their high school programs should be on the necessary work-related behaviors that help people to enter and remain in the competitive work force. (An Associated Work Skills Checklist is included at the end of this report. This list, developed at Teaching Research in Oregon, provides a list of skills that are often overlooked, but crucial if a student is to be a successful part of the working world).

When these and other suitable methods are used for their preparation, severely handicapped workers are successful in many jobs — from food service and housekeeping work to more complex production work, including such procedures as the assembly of bicycle brakes and drill machines. Many are capable of long-term employment in the competitive market. Their ability to learn and their remarkable work potential are the strongest reasons for improving and extending the vocational and career education opportunities available to them.

Learning and Working in the Community

If handicapped individuals are to lead productive lives in their own communities, then it is wise to train them for vocational opportunities that are available in the community. In rural areas, organizing meaningful work-study programs may be difficult because of the small number of handicapped youth enrolled and the limited number of professionals available to operate a program. But vocational opportunities do exist in rural areas, and a greater use of parents and community members as volunteers in training and monitoring severely handicapped students can be accomplished in any community in the United States.

Other difficulties may confront metropolitan centers, where sheltered workshops and activity centers can accept few new trainees because of shrinking budgets and because they are full and, in most cases, people have been on their waiting lists for several years. Thus, major demands are being made of the public schools to train severely handicapped students in pre-vocational, vocational, and career education. At the same time, school districts generally do not have the funds to pay for work experience in the community; most employers do not have payroll money to compensate youth for working in their businesses while in training; many business people have had no experience with severely handicapped students and are not eager to accept them as on-the-job trainees; and many schools do not have enough personnel to operate job training extensively in the community.

In some cities, partnerships between education and business and industry are helping to solve these problems. For example, the Chamber of Commerce in Dallas, Texas, coordinates city-wide business involvement in the public schools' career development program and in job training and placement in nine high schools. A very successful feature is the Adopt-A-School program, under which 632 businesses "adopted" Dallas schools in 1981-82, providing volunteers, materials, equipment, scholarships, programs, speakers, experts, and enrichment activities. Although the Dallas program is not directed exclusively toward handicapped students, it shows the resources and benefits to be gained through strong alliances with local business people.

A different approach was taken by the Lifelong Career Development Project for Handicapped Individuals, conducted by the University of Missouri-Columbia with funds from the U.S. Department of Education's Special Education Programs office. In this project, methods were developed whereby adults and young adults with disabilities (including cerebral palsy, epilepsy, hearing impairment, mental retardation, multiple handicaps, crippling conditions, and visual impairment) could receive post-school, lifelong career development services in a coordinated and continuous fashion. This model, which included training of various personnel to operate it, was established at three community colleges. These sites offered: (a) a normalized setting; (b) links with community agencies for greater cooperation in meeting the needs of the handicapped; (c) a focus on career development for the handicapped as employees, homemakers, volunteers, or participants in productive work not associated with employment; and (d) services in a central location where people can seek services, as needed, throughout adulthood.

Technology

As new informational, educational, and production technologies change the nature of the work place, new problems, challenges, and opportunities are arising in the education and training of handicapped children and youth. Some educators are exploring what is being done and what could be done with microcomputer hardware and software for students with severe perceptual, motor, and intellectual impairments. Others are using new technologies for vocational and career preparation or preparing handicapped youth to enter vocations in high technology.

A federally funded project at the Parsons Research Center in Kansas is developing a program to reduce the amount of time required in vocational training of severely handicapped youth by designing picture instruction and computer-assisted instruction that makes the student less dependent on his trainers. The priority is to place students in competitive employment positions, rather than in sheltered workshops or work activity centers.

In Richmond, Virginia, another federally funded project is demonstrating an innovative vocational education program for youth between the ages of 13 and 21 who have severe physical handicaps or multiple handicaps (but who are not mentally retarded). The specific focus is on training in high technology skills, which are in demand in central Virginia, and close ties are maintained with employers in business and industry.

Paid or Unpaid Training and Employment

A nationwide project, run by the Vocational Studies Center at the University of Wisconsin-Madison, has just been funded to help special educators enroll handicapped students in job training programs under the Job Training Partnership Act (JTPA). Under JTPA eligibility rules, up to 10 percent of program participants may be disabled. The project will identify each state's JTPA guidelines, and identify exemplary programs that serve the handicapped. JTPA is expected to enroll more than 25,000 special education students before May 31, 1986 when the project ends.

As Federal, State, and local budgets have changed, there has been a reduction in wage stipend packages as a means of support during on-the-job training. School district money for such purposes is becoming more and more scarce, and many businesses face economic difficulties that prevent them from paying young people for various jobs. Therefore, one of the barriers to employing severely handicapped youth in the community can be removed if pay is not a factor during training. This approach to overcoming barriers of attitude and expense has worked well in several locations.

In the Corvallis Public Schools in Oregon, students with severe mental retardation, autism, cerebral palsy, and multiple handicaps are provided non-paid vocational placement in community jobs for training purposes. In this program, volunteer assistants help with the training and monitoring of severely handicapped trainees' work performance. A similar program in Madison, Wisconsin, places adult severely handicapped people into the community on a non-paid basis at first, with the purpose of obtaining full-time employment for them after they have been trained on the job in a non-paid status. In both cases, this unpaid placement of handicapped trainees gives employers more knowledge of and experience with their capabilities and characteristics, causes the employer no expense, provides the training for the employer, and ensures that jobs assigned to severely handicapped youth will be accomplished. These features make it more likely that the employer will accept the severely handicapped student as a worker and will, in the long run, accept the student as a permanent worker.

With regard to non-paid employment, the President of the Ford Foundation has recently advanced this interesting, and concluding concept:

> Virtually every industrial country is now burdened with unprecedented rates of unemployment, especially among young people. . . . There is little doubt that a system of national service could have many desirable consequences for the economic future of the young. But those gains would be of a general nature, a by-product of fulfilling other national and individual needs. There is no way to produce enough jobs to go around except through a high rate of economic growth. And there is no effective cure for inadequate skills, inadequate education, and inadequate motivation except through substantial programs that address each of these problems.
>
> The national-service concept has been defined as 'an idea that recognizes that individuals can and should contribute to the larger society and that society should be structured to encourage such activity.' It rests on a belief that contributed service is a vital part of citizenship, an act that can bind us together as a people, accomplish needed tasks, and provide for individual growth and improvement. . . . Given a well-designed system, a period of service could open new perspectives for young people and new ways for them to better themselves as workers and as citizens.

Associated Work Skills Checklist

Associated work skills are the necessary work-related behaviors that help people to enter and remain in the competitive work force. Parents and instructors can use this list to record skills a student needs to develop or already has. The skills shown here are from *A Manual on Associated Work Skills for the Severely Handicapped*, by I. Egan, B. Fredericks, K. Hendrickson, J. Peterson, and W. Moore, published in 1983 by Teaching Research Publications, 345 North Monmouth Avenue, Monmouth, Oregon 97361.

Work Related Behavior

1. Checks own work
2. Corrects mistakes
3. Works alone without disruptions for specified periods with no contact from supervisor/teacher
4. Works continuously at a job station for specified amount of time
5. Safety:
    a. uses appropriate safety gear
    b. responds appropriately during fire drill
    c. follows safety procedures specific to classroom/shop
    d. wears safe work clothing
    e. cleans work area
    f. identifies and avoids dangerous areas
    g. responds appropriately to emergency situation (sickness, injury, etc.)
6. Participates in work environment for specified periods of time
7. Works in group situation without being distracted
8. Works faster when asked to do so
9. Completes work by specified time when told to do so
10. Time Management:
    a. comes to class/work for designated number of times per week
    b. arrives at class/work on time
    c. recognizes appropriate time to take break or lunch
    d. recognizes appropriate time to change task
    e. returns promptly from:
        1. break
        2. restrooms
        3. lunch
    f. uses time clock/clock appropriately
11. Observes classroom/shop rules
12. Does not leave work station without permission

Mobility/Transportation

1. Takes appropriate transportation to and from school/work
2. Locates work station/desk
3. Locates bathroom
4. Locates break/lunch area
5. Locates locker or coat area
6. Moves about class/work environment independently

Self-Help Grooming

Independently:

1. Dresses appropriately for school/work
2. Cleans self before coming to school/work
3. Cleans self after using bathroom
4. Cleans self after eating
5. Shaves regularly
6. Keeps hair combed
7. Keeps nails clean
8. Keeps teeth clean
9. Uses deodorant
10. Bathes regularly
11. Cares for menstrual needs
12. Cares for toileting needs
13. Eats lunch and takes break
14. Washes before eating
15. Brings lunch/snack independently
16. Operates vending machine
17. Uses napkin independently
18. Displays appropriate table manners

Social Communication

1. Communicates basic needs, such as:
    a. thirst
    b. hunger
    c. sickness
    d. toileting needs
2. Does not engage in:
    a. self-stimulatory or self-abusive behavior
    b. aggressive/destructive behavior
    c. self-indulgent (attention getting) behavior
3. Engages in relevant, appropriate conversation
4. Responds calmly to emotional outburst of others
5. Talks about personal problems at appropriate times
6. Refrains from exhibiting inappropriate emotions at school/work
7. Refrains from bringing inappropriate items to school/work
8. Refrains from tampering with or stealing other's property
9. Responds appropriately to changes in supervisors/teachers
10. Interacts with coworkers/students at appropriate times
11. Responds appropriately to social contacts such as "hello" or "good morning"
12. Initiates greetings appropriately
13. Ignores inappropriate behaviors/comments of co-workers/students
14. Refrains from inappropriate sexual activity at school/work
15. Laughs, jokes and teases at appropriate times
16. Responds appropriately to strangers

17. Approaches supervisor/teacher appropriately when:
    a. needs more work
    b. makes a mistake he/she cannot correct
    c. tools or materials are defective
    d. does not understand task
    e. task is finished
    f. disruption has occurred
    g. sick

18. Complies with supervisor's/teacher's requests in specified period of time
19. Responds appropriately to correctional feedback from supervisor/teacher
20. Responds appropriately to changes in routine
21. Follows instructions

Resources and References

Information in the first section is essentially from "Community Programs for Severely Handicapped Adults: An Analysis," by T. Bellamy, M. Sheehan, R. Horner, and S. Boles, which appeared in *The Journal of the Association for the Severely Handicapped*, 1980. 5(4), 307-324.

Overall Employment Trends

Assistant Secretary Madeleine Will spoke at the annual meeting of The Association for the Severely Handicapped (TASH) held in San Francisco, California on November 3-5, 1983. She cited the unemployment estimates, and called upon educators to include postsecondary or vocational goals in the individualized education plans (IEPs) of all handicapped secondary students, including the severely handicapped. Ms. Will's address is Assistant Secretary, Office of Special Education and Rehabilitative Services, Switzer Building, 330 C Street S.W., Washington, D.C., 20202; (202) 245-8492.

The Association for the Severely Handicapped is a membership organization for the exchange and improvement of practices for educating severely handicapped individuals. You may contact the Association at 7010 Roosevelt Way, Northeast, Seattle, Washington 98115; (206) 523-8446.

Information on unemployment among handicapped and nonhandicapped youth appears in *The Handicapped Adolescent: Innovative Practices in the Transition from School to Adult and Working Life:* A Report of an International Seminar Held in Scottsdale, Arizona, May 25-27, 1983, published by the Organization for Economic Cooperation and Development (OECD), Paris, France. A complete book of papers from the seminars sponsored by OECD and the National Association of State Directors of Special Education (Washington, D.C.) is available for $15, with a 20% discount for college students. Order from OECD Publications and Information Center, Suite 1207, 1750 Pennsylvania Avenue, NW, Washington, D.C. 20006: (202) 724-1857.

The Changing Scene

Information on changing the environment and changing the person is from *Lifelong Career Development for Handicapped Individuals*, by Donn E. Brolin and James T. Carver, published by the Department of Educational and Counseling Psychology, University of Missouri, 223 South Fifth Street, Columbia, Missouri 65211.

The Ability to Learn. Information about the learning abilities of severely handicapped people was reported by H. D. "Bud" Fredericks, Teaching Research Division, 345 North Monmouth Avenue, Monmouth, Oregon 97361.

Comments on the use of traditional tests with the severely handicapped are from "Research on the Vocational Habilitation of the Retarded: The Present, the Future", by Marc Gold, which appeared in the *International Review of Research in Mental Retardation*, Volume 6, Edited by N. R. Ellis and published by Academic Press, New York, New York.

Instructional strategies used with severely handicapped individuals, and vocational achievements of severely handicapped individuals have been reported in many sources. Among those who have worked directly in this area are: Lou Brown, Department of Behavioral Studies, College of Education, University of Wisconsin, Madison, Wisconsin; Paul Weham, School of Education, Virginia Commonwealth University, 901 West Franklin Street, Richmond, Virginia 23284; and Norris G. Haring, Washington Research Organization, 205-A Parrington Hall, DC-05, University of Washington, Seattle, Washington 98105.

Learning and Working in the Community. The overview of problems in rural communities was set forth by J. Gary Hayden in "A Work Experience Program in Rural Areas," in *Teaching Exceptional Children*, 1975, 7(4). This journal is a publication of the Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091; (703) 620-3660.

Recommendations on the use of volunteers and on the problems associated with vocational education for the severely handicapped in the public schools are reported by H. D. "Bud" Fredericks (address shown above).

The shrinking budgets and waiting lists of sheltered workshops and activity centers are discussed in *The Handicapped Adolescent: Innovative Practices in the Transition from School to Adult and Working Life:* (Full information on this report is shown above).

For more information on the Dallas Chamber of Commerce activities, contact Julie Thomas, Director of Career Education, Dallas Chamber of Commerce, 1507 Pacific Avenue, Dallas, Texas 75201; (214) 655-1351.

The Lifelong Career Development Project for Handicapped Individuals was conducted by Donn E. Brolin, Department of Educational and Counseling Psychology, University of Missouri, 223 South Fifth Street, Columbia, Missouri 65211.

Technology. A symposium exploring microcomputer hardware and software applications with severely handicapped students was conducted by the Media Production Project in Nashville, Tennessee in March 1983; participating institutions included the Trace Research and Development Center; the Society for Applied Learning Technology; the Kansas Neurological Institute and University of Kansas. For more information, contact the Media Production Project, Box 318, Peabody College/Vanderbilt University, Nashville, Tennessee 37203.

The Kansas technology project is being conducted by Charles Spellman, Box 738, Parsons Research Center, University of Kansas, Parsons, Kansas. The Virginia technology project is under the direction of Paul Wehman, School of Education, Virginia Commonwealth University, 1015 West Main Street, Richmond, Virginia 23284.

Paid or Unpaid Training and Employment. For more information about the project to help special educators enroll handicapped students in job training programs under the Job Training Partnership Act (JTPA), contact Lloyd W. Tindall, Project Director, Vocational Studies Center, 964 Educational Sciences Building, 1025 W. Johnson St., University of Wisconsin-Madison, Madison, Wisconsin 53706; (608) 263-3415.

The rationale for unpaid training opportunities, and the description of the Corvallis (Oregon) program are from "Community Based Vocational Training for Severely Handicapped Youth", by H. D. "Bud" Fredericks, *Counterpoint* (Counterpoint Communications Company, 750 McDonald Drive, Reno, Nevada 89503).

The Wisconsin program, operated by Patricia Beebe, is Vocational Education Alternatives, Inc., 14 W. Mifflin St., Suite 316.

The quoted material on national service was written by Franklin A. Thomas, President of the Ford Foundation, in "Support of National-Service System for Youths", in *Education Week*, June 6, 1983. The Ford Foundation recently made a substantial grant to a private group to evaluate several models of national service, measuring each against criteria of individual and social needs and operational and administrative feasibility. The final report, to be ready at the end of 1983, will estimate the likely costs and benefits of national service. The Ford Foundation is at 320 East 43rd Street, New York, New York 10017.

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Become Part of The National Exchange Network

With this newsletter, The National Information Center for Handicapped Children and Youth is inaugurating a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209.

Information from the National Information Center for Handicapped Children and Youth

November 1984

Self-Advocacy: How To Be A Winner

Tony Apolloni, Ph.D.
California Institute on Human Services, Sonoma State University, Rohnert Park, CA

RULES EXIST FOR MOST human service agencies which are designed to afford egalitarian treatment to all service recipients. We all know, however, that some disabled persons fare better than others. Why? Generally because either the disabled person or their parents are highly effective at influencing the people who administer and deliver their services. But how do effective self-advocates act? How does one self-advocate successfully?

Asking the Experts

One good way to find out what constitutes successful self-advocacy practices is to seek out successful self-advocates and ask. That's exactly what we did. Five professionally staffed regional advocacy agencies in California each identified three to five adults with developmental disabilities and four to six parents of persons with developmental disabilities whom they considered highly effective self-advocates, i.e., people successful in getting the services which they need. The participating agencies also each identified four or five human services professionals whom they felt would provide candid feedback on successful self-advocacy strategies. In all, 21 service recipients, 27 parents, and 21 professionals were interviewed.

A letter was sent to each of the interviewees to request their input, usually preceded by a telephone call explanation of the requested interview. The interviewer talked to most of the service recipients and parents in their homes. The professionals were generally interviewed in their offices. The semi-structured interviews were tape recorded and later summarized in writing. Most of the interviews lasted about one hour.

The Self-Advocacy Cycle

The information gleaned from the interviews was organized into a conceptual model for explaining successful self-advocacy strategies for use by service recipients and parents. A diagram of this model, termed the "Self-Advocacy Cycle," is shown in Figure 1. The self-advocacy cycle includes four stages:

1. **Targeting.** The process of identifying individual or family needs and the service agencies, if any, responsible to address these needs.

2. **Preparing.** The process of preparing to participate with service professionals in decision making sessions on how best to meet identified needs.

3. **Influencing.** The process of influencing decision makers within service agencies to adopt the self-advocate's desired approaches for addressing individual and family needs.

4. **Following up.** The process of checking to be certain that the agreements made by self-advocates and service professionals are carried out.

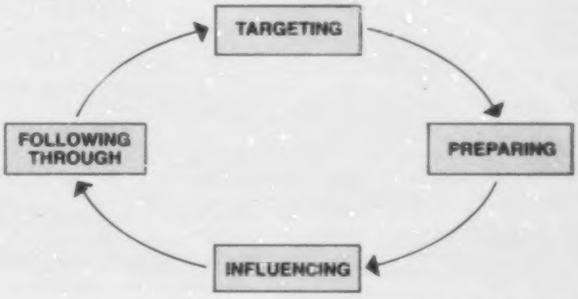

Figure 1. The Self-Advocacy Cycle for Use by Service Recipients and Parents in Obtaining Needed Services

Targeting Individual and Family Needs

The individuals whom we interviewed told us that the first step in the self-advocacy cycle is to identify the disabled person's needs and/or the needs of his/her family. This means that the disabled individual or parent must look at the child/adult's development and the status of their family critically. Stated from a parental perspective, useful questions include: Are you satisfied with the way your child is developing and the way your family is functioning? If so, why? Or if not, why? What would help you better assist your child's development and your family's functioning? What specifically is needed to help? Now? In the future? What agencies can give you needed advice, assistance, or services to help you now? In the future? What do you need to do to get these agencies to provide the needed help?

When targeting it is important to consider a wide range of possible needs. *Medical:* Is he/she healthy? Does he/she have the necessary assistive devices (e.g., eyeglasses, braces, wheelchairs? *Therapeutic services:* Does your child have problems which require a specialized therapist such as a physical therapist for large muscle development, an occupational therapist for fine motor development, or a speech and language therapist to learn to speak more clearly? *Behavior Management Assistance:* Are you able to manage your child's behavior? Is his/her teacher able to do so? Does he/she get along with peers? *Self-help:* Is your child performing at a satisfactory level in the areas of toileting, dressing, eating, and grooming? *Social/Emotional Development:* Does your child experience satisfactory relationships with family members, peers, other adults? If an adolescent, is he/she beginning to take part in social activities with agemates? Is he/she on the way to becoming a contributing member of the community? *Diagnosis and Assessment:* Are you clear about your child's specific problems? Do you understand the results of professional assessments? Do you feel that they were fair? *Educational Progress:* Is the school providing appropriate academic training and vocational preparation? Does his/her school placement represent the least restrictive alternative which is appropriate? Does it bring your child into positive contact with nonhandicapped peers? Does he/she like what goes on at school? *Recreation:* Is he/she involved in a social activity program? Does he/she engage in fun activities during spare time? *Living Arrangement:* Does his/her home (whether it is with you or away from you(afford a culturally normative lifestyle and still meet his/her specific needs? If out-of-home, are there a small number of roommates, caring and involved people, and opportunities to have daytime activities like other people? *Family Support Needs.* Are you able to take time away from your disabled child to do things such as vacation, go to medical appointments, shop, or visit with friends? Do you have family, friends, or a parent support group to talk with when you feel alone or frustrated? *Legal Services:* Are you familiar with your rights and the rights of your child? Do you need the services of a legal professional to advance your claim for services? *Monetary Needs:* Are your finances adequate to meet the needs of your handicapped child? Are you and/or your child eligible to receive financial assistance in areas such as respite care; therapeutic services; assistive devices; or income, food or housing subsidy?

Once you have identified your child's and family's needs in terms of the above categories and have prioritized them, the next question to ask is do you need outside help to meet your most significant needs. If the answer to this question is yes, the best ways to determine the availability of help are (a) visit a parent support group, (b) contact your state protection and advocacy office, or (c) communicate with local and state level voluntary organizations such as Associations for Retarded Citizens, United Cerebral Palsy chapters, and Associations for Autistic Children.

Knowledge of the available services and how they operate is an important first step. Parent groups in most local communities can assist you in getting needed information. (To locate the parent groups in your area write National Information Center for Handicapped Children and Youth, P.O. Box 1492, Washington, DC 20013). Parent groups can help you (a) determine your legal rights, (b) understand professional terminology, (c) identify the application and appeals processes of various agencies, and (d) prepare the documentation necessary to support your request for services.

Preparing to Influence Decision Makers

The interviewees stressed that you must be prepared in order to effectively influence decision makers. Having an experienced friend or advocate come with you to decision making meetings is one excellent way to improve your chances of getting needed services. An advocate may know the system better and a friend may supply extra support just by being there for you. At times, bringing the child/adult who is the focus of the meeting is appropriate, but it is usually not a good idea to bring along children who are not the subject of the meeting. Use your judgment.

Most of the interviewees advised that several other preparatory actions warrant careful consideration. First, build and maintain good relationships with the persons who are working directly with your child/adult. Second, come to meetings prepared to be *POSITIVE*, i.e. smile and be friendly, and leave any feelings of resentment or defensiveness at home. Third, get to know agency personnel, school board members, the school psychologist, legislators, etc. Find out their names, addresses, and telephone numbers so that you may contact them to seek help and information. Fourth, know your rights prior to requesting assistance from an agency. Few parents have the time to "know" all of the laws which are relevant to obtaining services. It is sufficient, and necessary, however, to know where to get this information. A federally funded protection and advocacy agency exists in each state which can inform you about the services which your child and your family may be eligible to receive. (To locate the P & A agency in your state write: Ethan Ellis, Pres. of National Association of Protection and Advocacy Agencies, Dept. of the Public Advocate, CN 850, Trenton, NJ 08625.) Fifth, be aware if the agency's services are offered on a mandatory or a permissive basis and if your child/adult meets the agency's eligibility criteria. What documentation should you have to substantiate your request for service? What is the agency's application process? Appeal process in the event that access to services is denied?

Influencing Decision Makers

Those interviewed all agreed that one of the most important things needed by self-advocates is good communication skills. It is just as important to know *HOW* to say something as it is to know what to say. Having good communication includes give and take and knowing how to develop empathy, i.e., to see the issues from the agency person's perspective. It also includes being assertive, as expressed through eye contact, posture, facial expressions, timing, and voice tone which communicates seriousness of intent.

The interviewees recommended that the telephone is one of the easiest, most effective advocacy tools at your disposal. Specific suggestions were offered for using the telephone to advocate:

1. Check whom you're talking to in order to avoid having to repeat your story.
2. Identify yourself and specifically state the purpose of your call.
3. Be prepared to describe essential aspects about your child/adult which are relevant to the agency which you are calling.
4. Be prepared. Have records available and encourage immediate action.
5. Be goal oriented. Know exactly the purpose of your call and stay on that purpose until it has been achieved.
6. Be assertive, yet positive and polite.
7. If your're unsatisfied, ask who else you may speak to.
8. Communicate a sense of teamwork. "How may we make that happen?"

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9. Know exactly what, when, and where your next steps are before hanging up.

Our advisors stressed that it is important for self-advocates to be aware of their personal presentation when meeting with professionals. Personal presentation includes body postures, facial expressions, dress, and interaction style. Most agency personnel react best to people who look and act like other agency personnel, i.e., people who dress neatly and control their outward emotional reactions. Being a self-advocate does not demand a "correct," "white middle class," or artificial presentation style, but we all have within us the ability to produce a variety of effects, to transmit many different messages. It's important when self-advocating to communicate a sense of self-confidence, personal competence, and determination.

The maintenance of a "paper trail" is perhaps one of the most important elements to being a successful self-advocate. A "paper trail" means documenting events and decisions which are important to your advocacy effort. Keeping a written record of what went on and when is often crucial when substantiating your position. Paper trail skills include letter writing, notetaking, and record keeping.

Letter writing is a tool which you can use to: (a) contact otherwise unreachable people; (b) document important interactions such as requesting services, requesting meetings, expressing a complaint, filing for due process hearing or appeal; (c) document time lines and deadlines; and (d) build accountability. Letters create pressure for a written response by the agency. If the person whom you write fails to respond within a reasonable time frame or refuses to consider your request, write again with a copy of your original letter attached. If you still do not receive an affirmative response, write their supervisor with copies of your previous letters attached and continue this chain of letters until you get an affirmative response or have exhausted the agency's levels of administrative ladder, i.e., have written at least two letters to the chief administrator and chairperson of the agency's board of directors. Your final recourse, aside from court action which is time consuming and costly, is to contact the agency's funding sources and perhaps local legislators. Be sure to append copies of all previous letters when contacting each person in a paper trail communication sequence.

Notetaking is a tool that provides a written record of what happened at a meeting or during a phone conversation. Notetaking signifies to others that you are an active participant in what is occurring. When you are taking notes people around you are more likely to feel accountable. They become more productive and responsible and pay more attention to you.

If you have never taken notes, notetaking may seem like a lot of bother. But once you practice, it becomes an effortless activity that you can easily do while fully participating with others in a group. Take notes at every meeting and conference that you attend so that you will have a record of all the information you receive. Also, keep a notebook by the phone so that you can keep a record of everyone you talk to and anything said which should be documented.

It is helpful to keep the following points in mind when taking notes:

1. At the beginning of your notes for a meeting, list the names and roles of all those present, and list the date, place, and time of the meeting. State the primary purpose of the meeting in one or two sentences.
2. Group the information into blocks according to topic such as (a) all information about assessment; (b) information about curriculum; and (c) information about placement.
3. Use an outline format and modify it to meet the needs of each particular meeting.
4. Write key words and abbreviations rather than long sentences. The fewer the words written, the more time available for thinking and actively participating.
5. Leave space along the left-hand margin for filling in answers to questions and for clarifying points which are not initially understood. Ask the speaker to clarify what he/she is saying if you do not understand.
6. Use a colored felt tip pen to underline important terms and phrases. This is very helpful when you go back later to review your notes.
7. It is sometimes helpful to organize information according to the questions asked and the various responses of each person at the meeting.
8. Before you leave a meeting, review your notes, be sure they are dated, and ask for any clarifications that are needed. It is sometimes a good idea (time permitting) to read your notes to others in the group in order to check for consistency and to remind everyone that what they have said is documented. If you type your rough notes, be sure and save the original rough notes in case of later misinterpretation.
9. File your notes in a home file.

Keep a record at home of reports and notes relevant to your child/adult's needs. You may wonder why this is necessary since case management agencies, schools, and residential programs already keep records on your child/adult. You are the primary person who will be with your child/adult in and out of programs, various placements, across locations and over time. It makes sense that you are the best record keeper of all.

Record keeping and maintaining a home file are useful in (a) organizing vital information about your child/adult for your own use, (b) taking files along to meetings so that officials will be aware of all relevant background information and of the organized manner in which you have approached the issues being considered, and (c) providing information to professionals when a new service is started or when you move.

The way in which you organize your home file is up to you. However, it is important for you to keep copies of every letter or other piece of correspondence which you write and receive regarding your child/adult, copies of reports, notes you take at planning meetings, and assessment results. There are many other items which you can add to this essential list.

A number of our informants emphasized that it is important (a) to distinguish your ideal goal from the minimum which you are willing to accept prior to entering a planning meeting and (b) to be willing to compromise when absolutely necessary. Planning meetings are "political meetings" in the sense that different points of view, all legitimate, must be harmonized. This is critical if all of the participants are going to feel good enough to work together cooperatively in the future. Keep an open mind and compromise when appropriate.

Following Up to Ensure that Agreements are Kept

It's unfortunate, but the mere fact that an agency agrees to provide a needed service does not always mean that the service will be provided in the promised manner. It's up to the self-advocate to check and see if the services which he/she worked hard to get are being delivered. You should periodically visit the services which are being delivered to your child/adult to see if they meet the specifications which were stated during decision-making meetings. When you visit a service program, bring along a note pad and your copy of the program plan for your child/adult. You may wish to ask if the objectives written in your child/adult's individual program plan are being met according to schedule. Moreover, you should ask yourself: "Am I happy with the services my child/adult is receiving?" "Has my input been incorporated in the services being received?" "Was the effort I expended to get these services worth it or do I feel that even after all that work on my part, the services are a disappointment?"

Be sure to check on the service environment. Is it neat and clean? Is it safe? Is it adequately equipped? Is it accessible to your child/adult? Is it adequately staffed? Is it warm, supportive, and happy?

Non-Functional Behaviors

The persons whom we interviewed indicated that self-advocates should be careful not to limit their effectiveness by demonstrating non-functional behaviors. The actions frequently listed in this general category included: any type of temper tantrum, emotionalism, tears, screaming, rudeness, empty threats, name calling, treating someone as your enemy, endless complaints, outrageous demands, trying to resolve too many issues simultaneously, trying to resolve an issue when a crucial person is absent, and utilizing the services of a lawyer too early.

Conclusion

The self-advocacy cycle is very much like a life cycle. Just as we go through different stages of development in our lives, parents go through different stages in advocating for their handicapped child/adult.

The self-advocacy cycle is made up of four stages. The first is the Targeting stage wherein you decide whether or not you are satisfied with how your child/adult is developing and your family is functioning, and what specifically is needed to help your child/adult to develop and/or your family to function more appropriately. It is a time in which parents seek out support and advice from friends and neighbors to help identify and obtain needed services; a time when parents seek out parent support groups to discuss their concerns with other parents.

The Preparation stage is a time when parents learn information needed to communicate to professionals working with the child/adult. It is also a time when parents become familiar with the laws pertaining to the rights of handicapped persons.

The Influencing stage is the point when you use the information gained during the Preparation stage to mobilize professionals into acting on your requests for services. It involves acting effectively in face to face and telephone meetings, effective written communication, and organized record keeping.

The final stage of the advocacy cycle is the Follow-up stage. This stage involves an assessment by the self-advocate of the services which are being received to assure quality outcomes. Follow-up activities are conducted to answer the question, "Am I satisfied with the services which are being delivered"?

The self-advocacy cycle is just that . . . a cycle. There is no end to the process of self-advocacy. Self-advocates must reassess their needs and the services available to meet their needs on an ongoing basis. Each stage in a person's development potentially means new needs, new decision-makers to influence, and new follow-up visits. Being a truly effective self-advocate is not an easy task! It demands tenacity and perseverance. In the words of one of the parents whom we interviewed, "Irritants make pearls."

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Information from the National Information Center for Handicapped Children and Youth
September, 1984

Teaching and Learning in Remote Schools: A Dilemma Beyond Rural Education

By Robert J. Scott
Superintendent, Humboldt County School District, Nevada Chairman,
Nevada Rural School District Alliance

MOST STATES WEST OF the Mississippi River experience problems associated with the fact that they encompass schools and school districts that are not simply rural, but are remote — isolated by distance and by geographic barriers from population centers, services, current information, and opportunities. Nevada is such a state.

Within a land mass of 110,540 square miles, Nevada's total population is only 917,870. The state is divided into 17 counties, which are also school districts. The average of 8.3 people per square mile takes into account the metropolitan centers of Las Vegas (Clark County) and Reno (Washoe County). Among the remaining 15 counties (or school districts), four average fewer than two people per square mile, and six average fewer than one person per square mile. In these counties, a small number of people are dispersed over thousands of square miles that contain few organized communities. For example, Nye County is the third largest county in land mass in the United States (18,064 square miles), yet its population density is only 0.85 per square mile. Its communities (with approximate population figures) are: Tonopah (8300), Pahrump (3600), Beatty (1200), Gabbs (900), Round Mountain (500), Amargosa (250), and Duckwater (200). Particularly in the latter five, the population tends not to be entirely clustered but to be dispersed over distance. Moreover, to travel from one of these communities to the others, consecutively, would require a trip of more than 2,300 miles. Therefore, of these seven communities, only Tonopah and Pahrump fall into the category traditionally defined as rural. The remaining organized areas and their schools are characterized by their remote nature.

Among the schools in Nevada's rural/remote counties, 26 are schools in which one, two, or three teachers are responsible for instruction of grades 1 through 8. Two of these 26 schools have three teachers. Three have two teachers. The remaining 21 are one-teacher schools. In these same counties, there are also 16 high schools with enrollments of 100 or less.

Remote schools are as far as 350 miles from a central administrative office. Many students in these areas of low population density spend up to two hours on a school bus, each day. Some adolescents live more than 100 miles from the nearest high school and therefore live in towns with relatives or in boarding homes in order to attend school. The logistics of travel to such extracurricular activities as sports events are out of the ordinary. A typical basketball trip in Humboldt County will include two games: one on Friday and one on Saturday. The travel will cover well over a thousand miles.

In many remote parts of the state, the population fluctuates dramatically in relation to fluctuations in the prices of gold and other metals that are mined here. Within a 30-day period, a district can lose a substantial proportion of its average daily attendance (and student turnover in a single school can be 50 percent or more) because the price of gold has fallen below a certain point and the mines shut down. Some superintendents check the Dow-Jones closings and the London gold fixings regularly, in the attempt to anticipate such events.

Nevada's remote areas also have multicultural concerns. Besides people of Hispanic origin, there are small clusters of of Basque, Cornish, Greek, Austrian, Japanese, and other ethnic groups, as well as several tribes of Native Americans, primarily Paiutes and Shoshones.

The Communities

The "community" may be a valley 50 miles long, with no residence within several miles of the school, or a much larger terrain with a very low population density. Residents make a living by ranching or mining; unemployment averages 15 to 20 percent.

Although there are physicians in some of Nevada's rural areas, there are none in its remote reaches. Babies are often delivered by fathers or midwives. Portable vans house well-baby clinics and provide vaccinations and other routine medical services periodically. Sheriff's rescue teams, helicopter medical evacuation teams, or forest rangers respond to emergencies, and people must often be transported well over 100 miles to reach a clinic and still farther to reach a hospital.

Since distance often precludes the formation of organized clubs or social organizations, the school tends to be the center of the community and the setting of many activities in which the adult population is directly involved. Community members feel that they own the school and have a stake in it.

Socially, there is more warmth and acceptance in these small communities than in cities. It is "hard to keep young teachers single," and no teacher will have difficulty becoming part of the community if he or she wants to. The community relates to the school as its center. The teacher is the center of the school and is regarded as an important and essential asset. Nor are parents passive with regard to the school. There is generally rapport and trust between parents and teachers, and far better cooperation by parents than is found in many urban centers.

The ability of a single teacher in a small, remote school has a powerful impact on the education of these students. What students learn is much more closely related to the skills and personality of the individual teacher than is true in large metropolitan schools.

Educational Characteristics

Remoteness causes difficulties in operating schools that districts traditionally defined as rural, urban, or suburban do not experience. State funding is not sufficient to provide the levels of service that other types of districts can provide. Curricula in remote areas are more limited than those in rural areas because of the high costs associated with offering a wide range of services and facilities for an even smaller student population. Whereas Nevada's rural schools can include physical education facilities, shops, and other features, small remote schools can offer little beyond the three R's.

Because there are no special services to provide art, music, counseling, physical education, library resources, or prevocational education, teachers in remote schools incorporate these into their own teaching agendas. In many cases, the resourcefulness of teachers, administrators, and community members has helped to fill these gaps. District-wide library books, resources, services, and instruction have been developed through innovative means in Elko and Nye Counties and, in the latter, the Gabbs library is operated by local residents. Churchill County has a kindergarten screening program, developed by teachers, staffed with county specialists, assisted by high school students, and involving parents. Elko County distributes kits covering the entire kindergarten curriculum for use by parents of young children in remote areas, and teachers in remote schools consult with parents on using these kits with their children. Instructional resource kits have also been developed for use by teachers of children who speak English as a second language.

All of Nevada's counties are investing in computers and in computer education. Some remote schools now offer computer education not only to students but also to area residents, and these classes have been excellent public relations tools for community involvement. The State Director of Special Education has made SpecialNet available to all districts, though this national electronic network for special education is not yet available to all of the schools.

Whereas instructional television and satellite transmission are being used successfully in traditionally defined rural settings, their use is often ruled out in remote districts because distance and terrain interfere with reception. Nevada's remote areas have no satellite stations nor mountaintop relays and, thus, no one in these areas is able to get decent reception on a television screen. Some schools are, however, using videotapes and videotape recorders.

In response to all of these contextual challenges, alternative strategies for Nevada's small remote schools include multigrade arrangements, itinerant services, assistance from multi-school principals, the employment of paraprofessionals, and rotating diagnostic-prescriptive services. The organization of eight grades in one, two, and three room schools is necessitated by small enrollments in remote areas and by the accompanying fiscal limitations regarding the teaching staffs that can be hired.

The frequency of special services varies from once a month to once a week. Nursing and psychological services are typically available once a month, whereas speech therapy is often available on a weekly basis. Some rural communities contract for the services of occupational and physical therapists, but the availability of such services in remote areas is highly unlikely. For visual, auditory, and psychological testing, some districts employ central office personnel who are qualified to perform these evaluations as itinerants; other districts purchase these services from agencies in metropolitan centers.

All but a few handicapped children in remote Nevada are taught in regular classrooms by regular classroom teachers. These are mildly to moderately handicapped children in grades 1 through 8. When a school serves no more than a dozen or so students altogether, a child with a mild to moderate handicap may not always be present in the service area's school-aged population. The high cost of providing special services to this small number of students, and the fiscal and logistical difficulties of deploying itinerant special educators over great distances restrict the provision of special education classes in remote areas. However, all graduates of Nevada's teacher education programs in elementary and secondary education must now have completed two courses in special education, and all practicing teachers must complete one course in special education and one course in multicultural education to be recertified. Similar requirements exist in many other states from which Nevada's teachers are recruited. Moreover, the mildly or moderately handicapped child in a remote school is not part of a multicategorical group of students with diverse types and degrees of disability; rather, he or she is usually the only handicapped member of the student group, and, as such, receives the considerable benefits that accrue from learning with and from nonhandicapped peers.

In 12 of the 15 counties with remote areas, school psychologists are employed to work with teachers and students on a referral basis. The other counties do not have school psychologists on the payroll, but purchase these services from another district or from the universities. If a student is identified as handicapped, the psychologist works with the teacher on a plan of action and assists in the development of an Individualized Education Program. The psychologist orders the materials indicated by the student's program and otherwise helps the teacher with its implementation. Speech therapists also travel to remote schools, setting up speech and hearing programs for parents and teachers to follow, monitoring programs and the progress of students, and providing additional assistance and materials, as needed.

Most school-aged children with severe or profound handicaps are either unserved, institutionalized, or receiving educational services in a metropolitan area. Although even the remote schools include children with physical handicaps and multiple handicaps of some kinds, the relatively small number who are severely mentally retarded, severely emotionally disturbed, deaf, or blind continue to receive services outside the school system. In Elko County, most of these children are enrolled in a private developmental center at the county's expense. There are also interdistrict agreements whereby severely handicapped students are placed in urban settings. The full inclusion of severely handicapped children and youth in remote schools in Nevada will take ingenious applications of technology; greater access to related services; considerably more interagency agreements; and special structural arrangements for itinerant services, home programs, and parent training.

The Teachers

Teachers in small remote schools have to be "competent generalists," with skills in individualizing instruction for all students, in planning instruction according to individual learning styles, in grouping children for instruction, in managing multiple activities, and in using creativity and ingenuity in working with children and using local resources. The nature of the remote schools requires, in essence, that all students have an individualized program, whether they are handicapped or not.

For example, the teacher in Denio (in Humboldt County) has 16 students over eight grades, which means that he has approximately 48 preparations (8 grades x 6 subjects). Each teacher in a multigrade situation has a similar workload. Each remote school employs an aide, and many aides and some teachers are also bus drivers. Denio is more than 100 miles from the district's central administrative office, and this distance makes inservice training, support services, colleague-to-colleague sharing, resource exchange, and every kind of communication difficult. However, the teacher in Denio, and the teachers in most of Nevada's remote multigrade schools, are succeeding in providing sound instruction.

The very best experience a teacher can have is that of teaching in a remote school. By mastering the multigrade classroom, these seasoned people have come to understand individual differences, instructional grouping, and the reinforcement of learning. They know curricular skill sequences across grades and subject areas; they understand direct instruction and increments of learning. They approach classroom instruction with the same logic that people use for problem-solving in everyday life -- by assessing the present situation or problem, determining steps to take to deal with it, taking those steps, evaluating the result, modifying the approach as necessary, reevaluating, and so on.

Veteran teachers in remote schools become experts at organizing peer tutoring and managing cross-age and cross-grade activities. They know how to use whole group sessions to develop inquiry and thinking skills in students. The situation in which they work enables them to grasp the relationships within curricular components. For example, when teaching phonics, one can simultaneously teach spelling. If a teacher is helping a student to identify the main idea in a reading lesson, that teacher can simultaneously be teaching the child how to develop the topic sentence in a paragraph. And, in teaching main ideas, one can use a science or social studies text, not just a basal reader, and thus the teacher and student can work with two subjects simultaneously.

Instructional practices such as these are paramount necessities in remote schools. We believe they are also essentials of good instruction, regardless of the geographic location of the school, and that they benefit both handicapped and non-handicapped students.

Housing Subsidies and Other Incentives

There is a common concern in rural and remote communities to find housing for teachers. In remote areas, both housing and utilities may be subsidized. In one area, the reduced rate is $100 per month for a three-bedroom house, and the teacher pays for utilities. In another, the teacher pays $100 per month for a trailer, and all utilities are paid for by the district. One county owns a multi-unit duplex for teachers in one of its rural townships; another owns a trailer court for teacher residences.

The base salary ranges between $13,500 and $14,500, plus employee benefits. Other benefits are also provided: counties pay the full pension costs (both the employer's and employee's shares) and, of course, housing costs are subsidized for all teachers in remote schools. One county still offers an isolation bonus for service to remote locations; the differential is $350 to $500 per year, based on mileage from the central administrative office. Aside from these rather modest incentives, people who have served at remote sites receive special consideration for other county jobs that open up.

Recruitment and Attrition of Personnel

Teachers in remote schools typically follow one of two patterns. Some stay for many years or for a lifelong career; others stay for one or two years and then depart. Administrators spend much of the summer recruiting. They have found job banks less effective than direct mailing of flyers to smaller colleges and universities across the country.

Districts cannot always fill open positions. The problem is not simply a matter of quantity, but also of quality, as it is preferable not to fill a position than to fill it with a person who lacks the skills to perform this very demanding role effectively. In cases of unfilled positions, a substitute or a multi-school principal takes the teaching role until a qualified teacher can be found. On occasion, the absence of a qualified teacher makes it temporarily impossible for a program to operate.

The Preparation of Teachers

Nevada's remote and rural schools are in need of adequately and appropriately trained teachers and paraprofessionals. Colleges and universities are generally not producing personnel who know how to handle multiple preparations, to individualize instruction, to understand curricular sequences across subjects and grades, to group and regroup students around learning tasks, and to apply other strategies necessary with heterogeneous groups of students. Teachers need to be sensitive to learning styles that are manifested by children in their classrooms. For most areas of Nevada, the matter of learning style is just as important as the language factor in children from other cultures, but too few teachers have been trained to respond to these variations. Teachers in rural and remote schools must particularly be critical consumers of materials, with the ability to identify and match instructional materials to individual student needs.

Adding the principles of special education to the preservice curriculum of all teacher trainees would be acceptable if all of these graduates developed competence in individualization of instruction, curricular sequencing, student grouping, and mastery learning. For those in remote, rural, and small districts, this is what genuine instruction represents. With more skilled generalists of this type, there would be fewer needs in any district of any size to label children as learning disabled, and fewer children would be categorized as slow learners or non-achievers.

If colleges and universities are concerned with preparing personnel for service in rural and remote areas, the only sensible approach is to send trainees to such sites for internships and practical experiences which emphasize the skills and understandings that are needed, and which expose students to the very positive features that exist in rural and remote areas. The University of Nevada in Reno does send preservice trainees for an internship in Elko County. These trainees come in pairs, and the county provides them with extremely inexpensive housing. Each trainee is supervised by the head teacher of a one, two, or three teacher school. Each also receives the same supervision that teachers receive from the multi-school principal, and each is also supervised by a university faculty member who generally visits twice during the internship. The university seems reluctant, however, to place trainees in situations where they cannot be immediately supervised by faculty members. This reluctance might be assuaged somewhat if higher education would appoint master teachers from remote areas as adjunct faculty members for the precise purpose of supervising trainee practica in such schools.

The greatest challenge is to re-educate or retrain teachers who are new to remote schools. It takes at least a month of assistance from the principal and others to orient personnel to the individualization and planning that must occur. While children in remote schools benefit from learning from each other, their teachers are often located too far apart to engage in much mutual exchange. If a teacher in a remote school has problems, however, most counties hire a substitute in order to bring the teacher together with a successful, long-term teacher from another school. The two teachers will teach together, eat together, and often share living quarters during this experience, and they almost always establish substantial and lasting contact. This has been the best tool for helping teachers to improve, and additional funding for this kind of professional development is much needed.

In some counties, teachers from remote schools may come together for a summer session in which they share and develop methods and materials. Elko County conducts two inservice workshops each year, which all teachers attend as part of their contractual agreements. These workshops improve attitudes and teaching skills demonstrably and should be available more frequently. Teachers in remote schools continue to need more training in procedures for educating handicapped students. The University of Nevada in Las Vegas provides training and technical assistance of this nature to teachers in the southern part of the state, and the Nevada Department of Education's Division of Special Education operates a Rural Assistance Project, which provides training and other services, but many remote teachers have to travel prohibitive distances to participate. Requests for inservice training are met by the State Department of Education or by the universities, but teachers need to come together much more frequently for training and information.

The Rural School District Alliance

The Nevada Rural School District Alliance was formed in 1983 to improve the quality of education available to those in outlying portions of the state. The Alliance represents rural and remote education in all of the 15 counties outside the state's two metropolitan centers. Local school boards have approved the concept, support local membership in the Alliance, and have allocated funds for its startup costs. This inter-district organization will provide rural and remote administrators with an open means of communication with one another, as well as a central information center where they can determine how similar districts are dealing with specific problems and questions. Unified efforts by all districts will increase each district's capabilities for providing quality programs.

A superintendent of schools from each region of Nevada sits on the Alliance's Board of Directors, which meets regularly to review and take action on requests from districts and to advance the planning of the Alliance. An Executive Secretary coordinates the program and plans for program funding.

Education in Nevada's remote areas represents the combined strengths of teachers, administrators, students, parents, local residents, and the resources that can be marshalled for this effort. Education in remote areas is also typified by difficulties and needs that are unique to each school, and by problems that are shared in common by all such schools. Without a concerted and unified effort, the strengths of remote education will not be sufficient to overcome the weaknesses. By stimulating leadership development and linkage among district leaders, the Alliance intends to help schools, teachers, students, parents, and the community to improve the quality of education in remote areas of the state. The short-term and long-term plans of the Alliance will address the problems and needs described in this report. Further information will be shared as the Alliance's programs develop.

ROBERT J. SCOTT is Superintendent of Schools for the Humboldt County School District, with administrative offices in Winnemucca, Nevada. As Chairman of the Nevada Rural School District Alliance, he may be reached in care of the Educational Research and Planning Center, College of Education, University of Nevada, Reno, Nevada 89557. *This newsletter is an abbreviated version of a longer working paper developed by the Alliance. To request a copy of the full report, send your name, address, and $2.00 to cover postage and handling, to the Nevada Rural School District Alliance at the above address.* Teachers and paraprofessionals who are interested in the challenge of working in Nevada, and in participating with the Alliance in improving the quality of education in rural and remote schools, should also contact Mr. Scott.

This article and the report on teaching and learning in remote schools were prepared as a mutual effort by Mr. Scott and other members of the Rural School District Alliance: ELMO DERICCO, Superintendent, Churchill County School District; F. GREGORY BETTS, Superintendent, Douglas County School District; CHARLES H. KNIGHT, Superintendent, Elko County School District; JAMES BULLOCK, Superintendent, Esmeralda County School District; SELWAY MULKEY, Superintendent, Eureka County School District; LEON HENSLEY, Superintendent, Lander County School District; NELDON MATHEWS, Superintendent, Lincoln County School District; HARRY DICKSON, Superintendent, Carson City School District; BARTON WALSH, Superintendent, Lyon County School District; ARLO FUNK, Superintendent, Mineral County School District; JOAQUIN JOHNSON, Superintendent, Nye County School District; JAMES P. KILEY, Superintendent, Pershing County School District; ORVILLE D. CULLEY, Superintendent, Storey County School District; and RUSSELL McOMBER, Superintendent, White Pine County School District.

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With this newsletter, The National Information Center for Handicapped Children and Youth continues a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209.

Information from the National Information Center for Handicapped Children and Youth

March, 1984

You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap

By Patty McGill Smith

IF YOU HAVE RECENTLY LEARNED that your child is developmentally delayed or has a handicapping condition, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a handicap, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of *denial*—"this cannot be happening to me, to my child, to our family." Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by feelings of *grief* and inexplicable *loss* that one does not know how to explain, nor how to deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?". Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?".

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of handicapped persons one has known. Sometimes there is guilt over some slight committed years before toward a handicapped person. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt*—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?". For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertantly let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the handicap.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?", or "Why my child?", many parents are also saying, "Why has God done this to me?". How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?". One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a handicap is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a retarded boy.

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Handicapped Children and Youth has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to the National Information Center to get that local information.

Talk with Your Mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request *accurate* information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is *your* child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Bitterness and Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to be handicapped, one of the other things pointed out to me was that she was (and still is) a very healthy child. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have raised.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are somethings that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then to set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of our country, assistance is available to help you with whatever problems you are having. At the end of this paper, a person is listed who will help you get started in gaining the information and assistance you need. While finding programs for your handicapped child, keep in mind that programs are also available for the rest of your family, too.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel *with* another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say, or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This Is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

Patty McGill Smith has recently moved to Washington from Omaha, Nebraska with her two youngest daughters, Marianne, age 17 and Jane, age 13. Jane, who was diagnosed at 14 months of age, has a mental handicap and epilepsy. She has been the source of inspiration for her mother's writing and her second career.

Patty's first career was at home raising seven children. The five older children are currently in five other cities of the mid-west. They are involved in careers in law, mental retardation, biology and two are in their first year of college.

The second career for Patty began as the staff coordinator of the Pilot Parents Program of the Greater Omaha Association of Retarded Citizens. This eventually became a four state center for Pilot Parents and a national resource for information about parent to parent programs.

In 1979 Patty moved to the Meyers Children's Rehabilitation Institute at the University of Nebraska Medical Center where she coordinated statewide services for parents, siblings, advocates, and professionals working with parents.

On January 16, 1984, she became Deputy Director of the National Information Center for Handicapped Children and Youth. Patty views this as a "wonderful opportunity" for a parent to serve as the link and liaison to parent organizations and groups nationwide. One of her major responsibilities will be to facilitate the exchange of as much current information and support among parents as possible. She invites parents everywhere to send information about the programs and the good things that are happening in helping parents where they live. Parents in need of assistance may write to:

Patty Smith, *Deputy Project Director*
National Information Center for Handicapped Children and Youth
1555 Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209

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Become Part of The National Exchange Network

With this newsletter, The National Information Center for Handicapped Children and Youth continues a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209

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PARENTS HELPING PARENTS
AND OTHER
PARENT SUPPORT ACTIVITIES

As the parent of a handicapped child, you are part of a group that includes millions of mothers and fathers across the United States. Like you, these parents want the best education and the best life for their children. Most of these parents have become quite involved in making sure that these things happen.

Parents have always played a vital role in the establishment of programs for their children. Parents founded such major national organizations as the Association for Retarded Citizens and the Easter Seal Society. Parents' efforts contributed largely to the passage in 1975 of Public Law 94-142 (The Education for All Handicapped Children Act). And parents like you, in thousands of communities, participate in groups that continue to make possible a better life for handicapped individuals and their families.

Parent groups have several functions: direct services for children; mutual support; training; advocacy; and communication.

Direct Services for Children

Parents who have seen the need for certain educational or other services have created and operated programs that provide these services for children with handicaps. They have hired teachers and other professionals, arranged for facilities and financing, and set policy for the programs. When The Education for All Handicapped Children Act became law, the public schools began to provide services that had until then been available mainly through parent efforts.

Some parent-operated programs continue to fill gaps in the spectrum of services provided to children and youth. For example, in some communities parents have established day care centers for very young children with handicaps. Elsewhere parents have spearheaded arrangements for community living so that young adults with handicaps can live independently. Parents have been the catalysts to begin respite services, recreational programs, and other needed supports for families. In these and other ways, parents can make a powerful difference in designing, operating, and monitoring programs and services for their handicapped sons and daughters.

Mutual Support

When people share common experiences and feelings, they give each other emotional and intellectual support. When parents join together in groups, they find:

- Acceptance, friendship, compassion, and understanding;
- New approaches to solving problems;
- Practical ideas for action and for working with their children;
- An awareness of common needs and common strengths;

- Greater self-understanding and insight;
- Reactions and advice from others who share their situations;
- Opportunities to express their emotions; and
- Meaningful relationships with other parents and less isolation in bringing up a handicapped child.

Being a parent is a complicated and demanding responsibility. Being the parent of a handicapped child is even more complex and demanding. The presence of a child with a handicap may affect family life and change relationships between mothers and fathers and other members of the family. Some parents say they especially need emotional strength at certain milestones in their children's lives (such as the time of the initial diagnosis, the child's first day of school, and the time when parents begin to consider the maturing child's employment possibilities). Sharing experiences and feelings with other parents, and mutually supporting one another, can be an important value of a parent group.

Parent Training

The average parent is not prepared to meet the needs of a child with handicapping conditions. Normally, parenting any child is a challenge. When you add the dimension of special needs, it is often difficult for parents to feel adequate in their parenting skills. At all ages and stages of a child's life, there is a need for the expansion of the parents' skills. Parent training may take many forms. During the early years of a child's life, parents focus on early learning, acquisition of self-help skills, and discipline. Later, parent training needs are adapted to the child's growth and development. Parents learn in one-to-one situations with medical personnel and educators in the early years. Other opportunities are in group situations. Group learning has the added benefit of peer interaction. This provides an opportunity for mutual support and understanding.

Many parents constantly add to their education by reading and reviewing pertinent information. Parents learn many skills from one another in various parent interactions. Others seek formal education in higher education classes. Whatever the form of training, view the process as an ongoing opportunity to prepare you to feel competent as your child's most important teacher.

Advocacy

As advocates, parents stand up for their children's rights and opportunities. There is a significant and continuing role to play in ensuring a free, appropriate public education and other rights for children with handicaps. The history of improved services for children with handicaps has demonstrated what can be achieved when parents act together and with other advocates for the handicapped. Several parent coalitions (listed at the end of this article) inform parents of their rights and help them to communicate effectively with the professionals involved in their children's lives. Others train parents on how to be advocates for their children. All are excellent sources of information on programs and services for the handicapped. These coalitions operate with the support of Federal funds, local funds, private contributions, or combinations of these resources.

A national agency, the Children's Defense Fund (122 C Street, NW, Washington, DC 20001) provides information about advocacy and operates a toll-free information line on the latest public policy and regulations affecting children. (Call 800/424-9602.)

Communication

Parent groups may provide information at meetings and seminars, and in newsletters and other publications. Many also operate telephone hot lines, and all make it possible for parents to share their own information resources.

Thus, parents can find out what they need to know from the implications of Congressional actions to specific suggestions for child management.

WHERE TO GET IN TOUCH

Three parent groups that were started at the grassroots level and now have many local chapters are Parentele, Pilot Parents, and the National Parent CHAIN. Each of them involves parents of children with any type and severity of handicap.

Parentele: An Alliance of Parents and Friends Networking for Those With Special Needs

Parentele grew out of parents' needs to communicate with each other and work together to meet the needs of their sons and daughters. The organization has representatives in each state, and its Board has adopted these statements of their philosophy:

- We believe that persons with handicaps are valued, developing human beings with the potential to grow and contribute to society;
- We believe that parents are the key to developing these potentials;
- We believe exchange of information provides support and assistance to parents;
- We believe in parents' promotion, advocacy, and monitoring efforts;
- We believe the expertise unique to parents makes a valuable contribution;
- We believe in a national linkage to strengthen and encourage parents.

For more information, write to: Patricia Koerber, 1301 East 38th Street, Indianapolis, IN 46205; or Elaine Clearfield, 310 South Jersey Street, Denver, CO 80224.

Pilot Parents

A group of parents of mentally retarded children started Pilot Parents in Omaha, Nebraska, in 1971. In 1974 the organization expanded to include parents of children with any handicap. Pilot Parents groups train parents to help other parents of handicapped children in times of special need, such as at initial diagnosis. For more information on finding or starting a Pilot Parents group in your area, contact Keryn Paul, Omaha Association for Retarded Citizens, 3610 Dodge, Omaha, NE 68131.

National Parent CHAIN: Coalition of Handicapped Americans Information Network

National Parent CHAIN is a recent effort to unite parent and parent/professional groups across the country. Its major goals are:

- To link existing parent coalitions, alliances, and other groups for information sharing purposes;
- To disseminate timely information electronically;
- To serve as a communications link between the States and the Federal government; and
- To affect State and public policy regarding the handicapped.

For more information, write to: National Parent CHAIN, 515 West Giles Lane, Peoria, IL 61614.

Specific Disability Groups

The National Information Center for Handicapped Children and Youth has information about national organizations and other parent groups. The addresses of national organizations are listed on the Fact Sheets on Specific Handicaps. State chapters of many organizations are shown on the accompanying State Sheets. The State offices have information about chapters even closer to you, which you can obtain by writing or calling them. The National Information Center for Handicapped Children and Youth has information about parent groups that serve parents of children with rare syndromes and also unaffiliated local parent support groups. For these names and addresses, contact us directly at

Post Office Box 1492, Washington, DC 20013.

Federally Supported Parent Programs

The Division of Personnel Preparation, Special Education Programs has addressed the training of parents for a number of years. By 1980, 10 projects were funded to begin a network of parent coalitions. A coalition is described as one made up of a broad spectrum of parent groups proposing to attend to the training of parents in the rights they and their handicapped children have under Public Law 94-142, and the ways they can exercise those rights in ensuring that their children receive a free, appropriate public education. The intent of the training is not adversarial, but a trained, knowledgeable group that works with the schools and other related service agencies to ensure appropriate programming for handicapped children." Currently, 31 parent projects are supported. They are:

Team of Advocates for Special Kids
1800 East Laveta
Orange, CA 92666
Director: Jean Turner

Georgia Association for
Retarded Citizens
1851 Ram Runway
Suite 104
College Park, GA 30337
Director: Mildred J. Hill

La Grange Area Department of
Special Education
1301 West Crossit Avenue
La Grange, IL 60525
Director: David W. Peterson

Task Force on Education for
the Handicapped
812 East Jefferson Boulevard
South Bend, IN 46617
Director: Klemens S. Bartosik

D.C. General Hospital
Department of Pediatrics
19th & Massachusetts Avenue, S.E.
Washington, DC 20003
Director: E. Elaine Vowels

Designs for Change
220 South State Street
Suite 1616
Chicago, IL 60604
Director: Donald R. Moore

Coordinating Council for
Handicapped Children
220 South State Street
Chicago, IL 60604
Director: Charlotte Des Jardins

Southern Illinois University
Department of Special Education
Carbondale, IL 62901
Directors: Priscilla Presley and
Norma Ewing

Federation for Children with
Special Needs
312 Stuart Street, 2nd Floor
Boston, MA 02116
Director: Martha Ziegler

New Hampshire Coalition for
Handicapped Citizens, Inc.
P.O. Box 1422
Parent Information Center
Concord, NH 03301
Director: Judith Raskin

Lehman College
CUNY Research Foundation/H.H.
Bedford Park Boulevard West
Bronx, NY 10468
Director: Brian Hurwitz

Appalachian State University
Human Development Research
Institute
Western Carolina Center
Morgantown, NC 28655
Director: Max Thompson

Ohio State University Research
Foundation
National Center for Research
in Vocational Education
1960 Kenny Road
Columbus, OH 43210
Director: Martin Richards

Western Oregon State College
Special Education
345 North Monmouth Avenue
Monmouth, OR 97361
Director: Thomas D. Rowland

Resources for Human Development Inc.
Action Alliance of Parents/Deaf
120 West Lancaster Avenue
Ardmore, PA 19003
Director: Roberta Thomas

Association de Padres Pro
Brenstar de Ninos Impedidos
de Puerto Rico, Inc. (APNI)
P.O. Box 21301
Rio Piedras, PR 00928
Director: Carmen Selles

PACER (Parent Advocacy Coalition for
Education Rights)
4701 Chicago Avenue South
Mineapolis, MN 55407
Directors: Paula Goldberg and
Marge Goldberg

Southern Nevada Association for the
Handicapped
1918 Pinto Lane
Las Vegas, NV 89106
Director: Vincent Trigg

Montclair Board of Education
22 Valley Road
Montclair, NJ 07052
Director: Stephanie Robinson

Advocates for Children, Inc.
24-16 Bridge Place South
Long Island City, NY 11101
Director: Miriam Thompson

Southwestern Ohio Coalition for
Handicapped Children
Social Information Center
3024 Burnet Avenue
Cincinnati, OH 45219
Director: Thomas Murray

University of Oregon
Center on Human Development
901 East 18th Avenue
Eugene, OR 97403
Director: Diane D. Bricker

Teaching Research
Oregon State System of Higher
Education
345 North Monmouth Avenue
Monmouth, OR 97361
Director: William Moore

IIA of World University
Barbosa Avenue Esquina
Guyama Street
Hato Rey, PR 00917
Director: John Hennig

Education Advocacy for Children
With Handicaps (EACH)
P.O. Box 120731
Nashville, TN 37212
Director: Harriet J. Derryberry

Parent Educational Advocacy
Training Center
228 South Pitt Street
Room 300
Alexandria, VA 22314
Director: Winifred Anderson

PEP Coalition (Parent Education
Project)
United Cerebral Palsy of
Southeastern Wisconsin, Inc.
Suite 434
152 West Wisconsin Avenue
Milwaukee, WI 53203
Director: Liz Irwin

West Virginia Department of Education
Office of Special Education
Capitol Complex, Building 6
Room B-309
Charleston, WV 25305
Director: William L. Capehart

PAVE (Parents Advocating Vocational Education)
1515 North Orchard
Tacoma, WA 98406
Director: Martha Gentili

Center of Development Disabilitites
499C Waterman Building
University of Vermont
Burlington, VT 05405
Director: Wayne L. Fox

Parent to Parent National
University Affiliated Facility
The University of Georgia
850 College Station Road
Athens, GA 30610-2399
Director: Sally B. Carter
(Funded by the Department of Health and Human Services)

Information about Parents Helping Parents and other parent support activities is continually expanding. Please keep the National Information Center for Handicapped Children and Youth informed about activities so that the information can be shared with other parents in your area. Innovative ideas and successes need to be shared. For new parents, there is a great deal of information available. Take and use what is helpful for you. Begin an information file and keep track of ideas, etc., that may be useful later. Keep in touch.

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Teaching Children with Handicaps: Some Implications

This fact sheet is for classroom teachers whose pupils now include children with handicaps; for special education teachers who are experienced with one kind of handicap but wish to know something about others; for resource room teachers whose classrooms may contain children with many different handicaps; and for administrators and supervisors who want to know more about educating all children, including children with handicaps.

Dealing with a child who has handicaps is *dealing first with a child*. All children learn differently, and the teacher's challenge comes in recognizing and adjusting to the individual. Thus, the ideas that follow are simply suggestions, which teachers should accept, reject, or modify to match the needs and characteristics of individual children.

In general, when a student with a handicap enters a regular class:

1. Obtain background information prior to the student's enrolling in your class, if possible. You will find pertinent information about teaching children with the same type of handicap in journals, books and magazines.
2. Elicit assistance from resource room teachers, therapists and other professionals involved in the care of the child.
3. Ask the student and parents about special provisions or adaptations that may help the student.
4. Encourage the student to be as independent as possible. It may require effort on your part to keep from helping the student with a difficult task. If it is within the student's ability, encourage but don't intrude.
5. Discuss the nature of the handicap with the other students when appropriate. Your attitude toward the handicapped student will determine largely how the class responds. Emphasize that all students are more alike than different.

When working with a student who has mild mental retardation:

1. Set realistic goals for the student, keeping environment and abilities in mind.
2. Carefully sequence learning activities, from easy ones to difficult ones.
3. Use concrete concepts and simple phrases in your explanations.

When working with a student who has a severe handicap:

1. Work closely with parents to choose goals, teaching methods and evaluation strategies. Try to keep home and school programs consistent.
2. Use materials, reinforcers and methods that are *chronologically* age-appropriate.
3. Emphasize repetition and provide opportunities for using the skill once it has been learned.
4. Promote skill generalization; teach the same skill in diverse settings.
5. Provide as many opportunities for interaction with non-handicapped peers as possible.

When working with a student who has a learning disability:

1. Use highly structured methods. Tell the student exactly what is expected.
2. Understand that a learning disability may cause inconsistent performance across subject areas.
3. If the child has a receptive language problem, use short sentences and simple vocabulary at first.
4. Allow students who have difficulty with written language to use tape recorders or the carbon copied notes of fellow students.
5. Use self-correcting materials for immediate feedback without embarrassment.
6. Provide ample opportunities for drill and practice.

When working with a student who has emotional or behavioral problems:

1. Provide adequate structure in the learning environment. Let the student know what is expected, but also indicate where there may be some flexibility.

2. Reinforce appropriate behavior; ignore inappropriate behavior. Model and explain what constitutes appropriate behavior.

3. Expect improvement on a long term basis. Understand that small gains may take time to become permanent.

4. Be sensitive to individual differences. Try to create an atmosphere where students are respected and learn to respect others.

When working with a student who has visual problems:

1. Before the school year begins, acquaint the student with the classroom and the school.
2. Teach other students the sighted guide technique or other ways to help without sacrificing the student's independence.
3. Keep background noise to a minimum.
4. Encourage the student to use a tape recorder or other special equipment in class. (Few blind people actually learn and use braille.)
5. Set an example for the other students in the class by describing the things you see and relating them to their sounds.
6. Give the student ample opportunity and assistance to structure personal space.
7. Find out how much residual vision the student has and make sure that lighting is appropriate.

When working with a student who has a physical disability or other health impairment:

1. Ask the student about aids and adaptations he or she may use.
2. Find out from parents or therapists what physical or medical limitations the child has, if any.
3. Don't do unnecessary things for the student. If he or she appears to want help, ask first.
4. Encourage the student to participate as much as possible in the regular school day.

When working with a student who is deaf or hard of hearing:

1. Before the school year begins, acquaint the student with the classroom and the school.
2. Seat the student where he or she can see your lips clearly.
3. Don't speak with your back to the class or with a bright light behind you. Don't inadvertantly cover your mouth when you speak. Try not to pace or walk around as you speak to the class.
4. Body language and gestures help students with hearing impairments understand the message.
5. Speak in a normal tone of voice.
6. Become familiar with hearing aids or any other special equipment the student may use.
7. Write assignments and directions on the board or on handouts. Have a hearing student take notes for a hearing impaired student.
8. If the student uses the services of an interpreter, do not talk to the interpreter. Rather, talk directly to the student. The interpreter will translate what you say; there is no need to funnel requests or questions through the interpreter.
9. After a lesson, clarify any problems the student may have.

For more specific information, write for one of our fact sheets on specific handicaps or contact the organizations listed in the last section of this fact sheet series.

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Attitudes

Teacher Attitudes and Expectations

Your attitudes toward students with handicaps set the tone of the classroom and shape the interactions among students. One important aspect of attitude is *expectation*. Research findings have repeatedly emphasized the influence of teacher expectation on student performance. If teachers expect students to be behavior problems, students may very well fulfill this expectation.

Labels may affect expectations. Frequently, labels introduce a set of preconceived characteristics (a stereotype) causing a teacher who is assigned a class including a handicapped student to envision a specific behavior pattern before even meeting the student. You should be aware of your own attitudes and expectations and should ascribe to labels no greater import than the information they provide about how the student learns and what services the student needs.

Student Attitudes

Placing students with handicaps into the "mainstream," or regular class, does not guarantee that they will be liked, accepted, or chosen as friends by their nonhandicapped peers. Without careful attention by sensitive teachers, such a placement could even be a harmful experience.

You will find that working closely in advance with the parents, the student, and the resource or special class teacher, may be instrumental in preparing the student with handicaps for regular classroom experiences.

To prepare the class for the entry of a student with handicaps, focus on students' similarities rather than differences. Deal forthrightly and comfortably with students' questions, letting them know it is all right to discuss handicaps. Two other approaches can promote positive relationships among students: encourage cooperative learning tasks and establish ways for students to help each other.

Cooperative Learning

In small groups, students work together on tasks that encompass all the students' abilities. Cooperative learning is the opposite of competition, which may not be fair to all students with handicaps. To teach cooperation, the teacher must be ready to help by:

- Giving the student with the handicap a structured role in the group.
- Showing that each member of the group has different skills.
- Emphasizing that the best work will need everyone's contribution.
- Teaching students with and without handicaps how to cooperate.
- Adapting the tasks so that the student with a handicap can succeed. This may mean giving group members different tasks and using the average scores, varying the amount of work each member receives, or using improvement rather than performance scores.

Peer and Cross Age Teaching

Another way to promote acceptance among students is to encourage them to help each other. They do it all the time, informally. Given a little training, students can learn how to teach and encourage their peers, and in the process they can improve their understanding of the subject and of themselves. Handicapped students do not always need to be on the receiving end. Their strengths can be used to help their classmates, and they can develop confidence in so doing. Students can be older than their "clients" (cross age teaching) or the same age (peer teaching).

Peer or cross age teaching won't work without some guidance from teachers. In regular sessions with the tutors, teachers can demonstrate methods of instruction and answer specific questions, especially about the tutor's feelings. Through role playing and keeping a journal, tutors can analyze their reactions to their "clients."

One unexpected benefit of the peer teaching approach is the effect it may have on the rest of the school. Tutors may begin to look out for their "clients" in other school situations—the lunchroom, for example. As students see their classmates assuming the tutor role, they may become interested as well, and associating with students who have handicaps may take on greater status. Above all, some real contact is being made between students who might otherwise never have gotten to know each other.

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Teacher Centers:

Teachers Helping Teachers

Teacher centers are grassroots organizations growing out of the needs of people who work with children. Nearly 400 Teacher Centers are operating across the country, usually closely connected with local resources and people.

Run primarily by teachers for teachers, most centers offer workshops or courses on topics identified as special needs. Training tends to focus on people's strengths and requests, rather than on their weaknesses.

Teacher centers typically provide drop-in services for materials construction. Teachers can use the tools and models for designing educational games, toys, or special equipment. Many centers also sell commercial materials.

Some teacher centers offer the services of "advisors." These are people who will come to a classroom to consult on specific areas of need which a teacher has identified. Many teachers find this one-on-one approach more helpful and less threatening than visits by supervisors or administrators.

Another function of teacher centers, and perhaps the most valuable one, is matching individuals or small groups of teachers with similar interests or goals. This "matchmaking" can range from very informal arrangement (two English teachers working on children's poetry) to structured and formal situations (a materials exposition that displays and explains teacher-made materials).

Becoming part of a teacher center can give you new direction and motivation. You may find that you can offer help to other teachers, too. In the process of sharing with other professionals you'll find the support that may make all the difference to you and to your students.

The financial structure of teacher centers is as varied as their services. Some are supported by local school districts, some by foundations, and others through membership or service fees. Still others do all kinds of fundraising to remain operational.

For More Information

If you know about a nearby teacher center, see how you can participate. If you don't know of one, call your state department of education and ask the person responsible for staff development. He or she can help you find out about starting one if none is available in your area.

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The Teacher/Parent Relationship

Teachers have a large share of responsibility for helping to open the lines of communication with parents of children with handicaps. Teachers are improving their listening skills, improving their "conferencing" skills, improving their skills in counseling parents regarding their child's education, and involving parents in the day-to-day education of children with handicaps.

Improving Counseling and Listening Skills

Teachers may find themselves in the position of counselor to parents. It helps to understand a few basic principles of this relationship and some techniques that others have found useful. (Counseling techniques are helpful in dealings between teachers and parents, but if there is a need for actual psychotherapy or counseling, a trained therapist should be consulted.)

Basic principles to keep in mind:

- Try to create an atmosphere in which parents feel comfortable and accepted.
- Assume that parents have good intentions.
- Try to meet with *both* parents.
- Answer questions quickly and clearly. Avoid using professional jargon.
- Expect to be criticized sometimes. Understand that some of the information you are conveying may be difficult to accept. Don't avoid saying things, or talk in cliches, but do think about the best way to express yourself.

A few techniques to try:

- Practice active and reflective listening. Active listening is trying to understand parents' feelings as well as the content of what they say. Reflective listening involves restating what the speaker has said to clarify and confirm statements.
- Become sensitive to nonverbal communication.
- Ask for clarification if you don't understand something.
- Try to listen without interruption.

The first step in the right direction is to let parents and other family members know that they are welcome to visit you and your classroom anytime. One teacher sends a letter to the parents of each student at the beginning of each school year. In the letter she asks for their ideas, introduces her own, and tells them that they may come visit at any time. If parents give her advance notice of a visit, she tries to prepare some work samples and set aside a few minutes to talk while the students are busy. If they are "in the neighborhood and want to drop by" she assures them they're welcome but can't guarantee she'll have time to talk. Of course, she reminds parents that they can volunteer in the classroom as tutors, aides, or guest speakers, in addition to the more customary assistance with trips and parties. Let parents know what they can do to support the school program. By the same token, ask them how you can help reinforce concepts or behavior at school.

Another way to involve parents (and an important requirement of Public Law 94-142) is to enlist their help in developing the child's Individualized Education Program. Make them a working part of the educational team.

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Kroth, R. *Communicating with Parents of Exceptional Children.* 1975. 1777 South Bellaire Street, Denver, CO 80222. ($5.95)

Lillie, D.L. and Trohanis, P.L. (Eds.) *Teaching Parents to Teach.* Walker and Company, 720 Fifth Avenue, New York. NY 10019. ($12.95)

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Classroom Management

These general guidelines for class management cluster in two areas: organizing the environment and directly controlling the students.

ORGANIZING THE ENVIRONMENT

The Physical Structure

Teachers organize the learning environment all the time, consciously or unconsciously. There are some very simple steps you can take to maintain order. For example, desks can be grouped in ways that encourage or discourage interaction among students, and learning centers can be set up to structure independent work or provide for small group instruction. Areas for rewards and punishment (time-out space) can also be designated.

Students with special needs may need special equipment. For example, young children with physical problems may need to use a prone board while doing fine motor tasks because positioning in a certain way gives them the greatest control over their movements. Therapists will advise you about these kinds of special needs, but incorporating the special equipment into the classroom routine will be up to you.

Seating considerations are another important aspect of physically structuring the class. Hearing-impaired children who rely on lipreading skills will naturally need seating that gives them a clear view of the teacher or other speaker with adequate lighting on the speaker's face. Distractible children may be best placed near quiet self-directed classmates, rather than beside other distractible children. Visually impaired students should be situated so that it is easy for them to find their seats and equipment (braille writers, low vision aids, or other aids).

The classroom should be organized so that all students can be as independent as possible. This means access to equipment, easy passage in and out of the classroom, and access to the chalkboard or to a central spot where written or audio instructions are kept.

Another important element in the physical arrangement of a classroom is the traffic pattern. It may be helpful to map out pathways that students use to get to various places in the room. Careful planning before you arrange the room will pay dividends later when students no longer distract each other when moving from one activity to the next. It is in that *transition* time—the period between tasks or classes—when students are most likely to be disruptive.

Scheduling

Many teachers find it useful to tell students what will be happening ahead of time and when. This is especially helpful for students who have difficulty changing gears (the hyperactive or perseverative child, for instance). A timer is one means of letting students know about an approaching schedule change, and it may help students assume greater control over their actions. Timers can be set for different intervals for different students.

In addition to transition times, other periods that should be built into the schedule include: major instructional time, reward time (for all students or specific students, based upon individual performance), and time for evaluating and reviewing learning.

Volunteers and Paraprofessionals

Some teachers are fortunate in having volunteers at their disposal. Others use and depend on teacher aides or classroom assistants. Both volunteers and paid assistants can help enormously, but only when they are given direction and feedback. Frequently they have creative ideas about new ways to approach learning tasks. They can also help you by giving that extra individual time a particular student genuinely needs but which you yourself cannot possibly give. In many schools, volunteers have been very valuable in helping to ease handicapped students' transition into mainstreamed classes.

An excellent resource for establishing a volunteer program is The National School Volunteer Program, Inc., 701 N. Fairfax St., Suite 320, Alexandria, VA 22314. The Retired Senior Volunteer Program and the Foster Grandparent Program in your community are possible sources of volunteers, as are local colleges and universities.

DIRECTLY CONTROLLING THE STUDENTS

Scanning

An effective yet often overlooked technique for behavior control is scanning the classroom every few minutes. Keeping track of the various groups in the class may help to prevent problems. Some teachers find that merely establishing eye contact with a student can forestall mischief. Detecting restlessness may allow you to intervene before misbehavior occurs. Also, of course, scanning reveals students who are having difficulty with their work.

Reinforcement

Teachers use reinforcements all the time: acknowledging good work, helpful attitudes, or contributions to the class. Unfortunately, it is also easy to reinforce negative behavior. Shouting at a student who may be misbehaving merely to get attention is one example of reinforcing negative behavior. Ignoring inappropriate behavior (whenever possible) is frequently more effective. Once behavior is acknowledged, it must be dealt with.

Removal from the group is another method that may control a student's behavior. Some teachers believe it is helpful to provide children with "time out" away from the others for short periods of time. Investigate the resources listed at the conclusion of this section and discuss the issues with a school psychologist or other team members.

One advantage of a straightforward reinforcement approach is that it helps students to understand what is expected of them and what the consequences of their actions may be. Sometimes teachers establish contingencies: if students complete the assignment they can choose a game or read on their own, or whatever is particularly rewarding to them. Sometimes, too, students can plan their own contingencies. Getting them involved in regulating their own behavior is a major milestone in helping them develop self control.

Stimulus Control

Teachers can also use cues or signals to control student behavior. This approach gives students guidelines for behavior, based on an agreed upon indicator. For example, flashing the lights may be a signal that students should return to their desks, or sounding a note on the piano may indicate time for a change of activities. Of course, these cues must be modified for students with sensory problems.

ADDITIONAL SUGGESTIONS

Every teacher has a special repertoire of practices for keeping a classroom under control.

- Teaching students how to react to other students' misbehavior.
- Letting active students do tasks that require them to be out of their seats for stated periods of time.
- Using peers as role models.
- Helping students find acceptable ways of venting frustration and aggression.

Class Management Resources

Fagan, S.A., Long, N.J., and Stevens, D.J. *Teaching Children Self Control.* 1975. Charles E. Merrill Co., 1300 Alum Creek Drive, Columbus, OH 43216. ($12.50)

Gross, S.S. and Ingersoll, G.M. *Management of Disruptive and Off Task Behaviors: Selected Resources, Bibliographies.* 1981. Eric Clearinghouse on Teacher Education, 1 Dupont Circle, Suite 610, N.W., Washington, D.C. 20036. ($5.00)

Lovitt, T.C. *What Research and Experience Say to the Teacher of Exceptional Children: Managing Inappropriate Behaviors in the Classroom.* 1978. Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. ($5.75)

Reynolds, M.C. (Ed). *What Research and Experience Say to the Teacher of Exceptional Children: Social Environment of the Schools.* 1980. Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091. ($7.50)

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Print Sources for Information

People who take the time to write to the National Information Center for Handicapped Children and Youth are information gatherers. We have prepared this list of other sources of information to help.

Newsletters

Various professional organizations publish newsletters for their membership. These newsletters may provide information on upcoming events and conferences as well as on practical aspects of teaching and/or advocating for children with handicaps.

Journals

The following journals contain practical information about teaching children with handicaps.

Academic Therapy, 28 Commercial Blvd., Novato, CA 94927 ($15.00/yr.)

Childhood Education, 3615 Wisconsin Ave., NW, Washington, D.C. 20016 ($32.00/yr.)

Counterpoint, 750 McDonald Drive, Reno, Nevada 89503 ($9.50/yr.)

Early Years, Allen Raymond, Inc., Hale Lane, Darien, CT 06820 ($13.00/yr.)

Exceptional Parent, Psy Ed Corporation, 296 Boylston Street, Boston, MA 02116 ($16.00/yr.)

Instructor, Instructor Publications, Inc., Danville, NY 14437 ($18.00/yr.)

Pointer, Heldref Publications, 4000 Albemarle St., NW, Suite 302, Washington, D.C. 20016 ($25.00/yr.)

Teaching Exceptional Children, 1920 Association Drive, Reston, VA 22091 ($16.00/yr.)

Young Children, National Association for the Education of Young Children, 1834 Connecticut Avenue, NW, Washington, D.C. 20009 ($15.00/yr.)

Books

The following books have specific ideas for classroom activities.

Affleck, J.Q. and others. *Teaching the Mildly Handicapped in the Regular Classroom.* Second Edition. 1980. Charles E. Merrill Publishing Co., 1300 Alum Creek Drive, Columbus, OH 43216. ($7.50)

Chapters address a model for systematic instruction.

Calhoun, M.L. and Hawisher, M. *Teaching and Learning Strategies for Physically Handicapped Students.* 1979. University Park Press, 233 East Redwood St., Baltimore, MD 21202. ($18.50)

Cartwright, C.A., Cartwright, C.P., Ward, M.E., and Willoughby-Herb, S. *Activities, Guidelines, and Resources for Teachers of Special Learners.* 1981. Wadsworth Publishing Co., Belmont, CA 94002. ($9.95)

Listing of activities and resources (films, books, manufacturers' addresses, professional organizations).

Charles, C.M. and Malian, I.M. *The Special Student: Practical Help for the Classroom Teacher.* 1980. C.V. Mosby, 11830 Westline Industrial Drive, St. Louis, MO 63141. ($[illegible].40)

Offers specifics on teaching behavior disordered, learning disabled, mentally retarded, speech impaired, gifted, visually handicapped and hearing impaired, orthopedically handicapped and health impaired students.

Choate, J.S. and Young, L.S. (Eds.) *Practical Educational Prescriptions for Students in the Mainstream.* 1982. Available from the ERIC Document Reproduction Service, P.O. Box 190, Arlington, VA 22210. ED 218857, 116 pp. ($9.15)

Activity suggestions developed by experienced teachers for mainstreamed students with difficulties in specific instructional areas of reading, mathematics, spelling, writing, and behavior. Suggestions include large group, small group or one-to-one exercises.

Cook, R.E. and Armbruster, V.B. *Adapting Early Childhood Curricula. Suggestions for Meeting Special Needs.* 1983. CV Mosby, 11830 Westline Industrial Drive, St. Louis, MO 63141. ($16.95)

Froehlinger, V.J. (Ed.) *Today's Hearing Impaired Child: Into the Mainstream of Education. A Practical Guide*

for Teachers, Parents, and Administrators. 1981. Alexander Graham Bell Association for the Deaf, 3417 Volta Place, NW, Washington, D.C. 20007. ($14.95)
Considers such topics as assessment, IEP's, tutorial skills, reading instruction, and use of oral interpreters.

Gappa, S. and Glynn, D. *Room to Grow: Creating and Managing the Self-Contained Special Education Class.* 1981. Pitman Learning, Inc., 6 Davis Drive, Belmont, CA 94002. ($6.50)
Provides guidelines for organizing and managing a self contained class for learning disabled children.

Glazzard, P. *Learning Activities and Teaching Ideas for the Special Child in the Regular Classroom.* 1982. Prentice-Hall, Inc., Englewood Cliffs, New Jersey 07632. ($14.95)
Specific ideas for teaching reading, math, writing, phonics, and language. Also a section on behavior management.

Hass, K., Kasper, K., Kryst, E.O., and Young, E. *Common Solutions for the Uncommon Child.* (K-8). 1982. Interstate Printers and Publishers, Inc., Danville, IL 61832-0594. ($7.50)
Prepared for regular teachers with mainstreamed students in their classes. A variety of strategies offered for profiles of children, (e.g. Stevie Squirmer, Augi Auditory, Spacey Tracy, and Zero Zelda).

Haglund, E. and Stevens, V.L. *A Resource Guide for Mainstreaming.* 1980. Charles C. Thomas Publisher, 301-327 East Lawrence Ave., Springfield, IL. ($14.75)

Hart, V. *Mainstreaming Children With Special Needs.* 1981. Longman, Inc., 19 W. 44th St., New York, NY 10036. ($8.95)

Koegel, R.L. *How to Integrate Autistic and Other Severely Handicapped Children into a Classroom.* 1982. H&H Enterprises, Inc., P.O. Box 1070, 946 Tennessee, Lawrence, KS 66044. ($4.00)
Provides step by step instructions for including autistic and otherwise severely handicapped students into regular classrooms.

Morsink, C.V. *Perspectives of an Ivory Tower Realist.* 1981. Available from the ERIC Document Reproduction Service, P.O. Box 190, Arlington, VA 22210. ED 202836, 154 pp. ($12.65)
The observations of a teacher educator who spent a semester in mainstreamed elementary classrooms. Illustrates classroom management, instruction, and grouping procedures.

Morsink, C. (Ed). *Mainstreaming: Making It Work in Your Classroom.* May 1981. Available from the ERIC Document Reproduction Service, P.O. Box 190, Arlington, VA 22210. ED 205479, 89 pp. ($7.40)
Information on materials and methods for elementary school teachers dealing with mildly mentally retarded children in the regular classroom.

Radabaugh, M.T. and Yukish, J.F. *Curriculum and Methods for the Mildly Handicapped.* 1982. Allyn and Bacon Inc., Longwood Division, Rockleigh, NJ 07647. ($21.81)
Includes five chapters on learning objectives and skill building sequences in math, reading, written expression, science and career education.

Rogovin, A. and Cataldo, C.Z. *What's the Hurry? Developmental Activities for Able and Handicapped Children.* 1983. University Park Press, 300 N. Charles Street, Baltimore, MD 21201. ($15.95)
86 materials for young children organized into physical, personal, and intellectual tasks. Ideas stress self learning and promote independence. Many photographs.

Sleeman, P.J., Messineo, L.V., and Rockwell, D.M. (Eds.) *Designing Learning Programs and Environments for Students with Special Learning Needs.* 1983. Charles C. Thomas, Publisher, 2600 South First St., Springfield, IL 62717. ($24.75)

Willoughby, D. *Your School Includes a Blind Student.* Second Edition. 1981. National Federation of the Blind, 1800 Johnson St., Baltimore, MD 21230. ($3.75)
Provides specific suggestions for successfully integrating blind children into regular classes. Topics addressed include chalkboard presentations, discipline, home economics, notetaking, grading, seating in the classroom, typing and vocational guidance.

Woodward, D.M. *Mainstreaming and the Learning Disabled Adolescent: A Manual of Strategies and Materials.* 1981. Aspen Systems Corp., 1600 Research Blvd., Rockville, MD 20850. ($27.95)
Provides information on intervention strategies for common educational problems and content area instruction.

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Information from the National Information Center for Handicapped Children and Youth

December, 1983

Proceedings From The 1983 National Parent Group RoundTable

Thirty leaders of parent groups and coalitions, representatives of specific disability groups, and other service providers met in Washington D.C. on August 2 and 3, 1983 at the invitation of the National Information Center For Handicapped Children and Youth. Participants discussed their work and brainstormed about the needs of children and youth with handicaps and their families. This report summarizes the training and information needs identified by parent leaders from across the country and presents some of the strategies that were proposed to meet those needs.

	TRAINING NEEDS	INFORMATION NEEDS
Parents and Families	• basic training in the law • basic training in parenting • advanced training in securing services • advanced training in improving services	• on the right to life-sustaining treatment for newborns • on the meaning of diagnostic categories and the validity of diagnostic tools • on how to evaluate the quality of programs that have been developed in compliance with the law • on their rights and responsibilities under the law and current case law • on ways to influence programs for their children, including better communication with professionals and policy-makers • on sources of help and support • on ways to make society aware of and responsible for the needs of their children from birth throughout adulthood
Children and Youth with Handicaps	• basic training on the law • basic training in reaching their full potential • basic training in becoming independent, productive citizens	• about growing up and the developmental stages of the life cycle • to empower them to make informed choices of their own • from and about their handicapped peers, that will help them create positive self-images • that will help them reach their potential and become productive independent members of society • about sexuality, nutrition, creative problem solving, and about coping with schools and parents from the perspective of their own special needs
Service Providers	• training in respecting the dignity of individuals with handicaps and their families • training in collaboration and teamwork, especially with parents	• from parents about their children and their families, including information about developmental, life cycle changes • about state-of-the-art research on handicapping conditions and quality practices • about the processes of collaboration and ways to work and communicate better with parents and other professionals • about changing attitudes and the predictive power of expectations • about community action and the process by which society allocates resources • about cultural differences and values between minority and majority populations
Parent Organizations and Leaders	• basic training in organizing public awareness programs • basic training in operating parent groups • advanced training in obtaining funding • advanced training in leadership skills	• from peers, regarding solutions to common problems • about techniques or practices that have proven effective • about the formation, maintenance, management and support of voluntary organizations • about changes, or contemplated changes, in policy or legislation that will effect their families • about ways to evaluate information for veracity • about successful community involvement programs and projects • about the needs and cultures of unreached parents • about leaders' personal survival and self-renewal

Training Needs

Professionals, be they medical personnel, service providers, or policy makers, all play important roles in improving the quality of life for children with handicaps. However, the people with the longest term, constant and most intense relationship with handicapped children are their parents. Parents play a central role in advocating for children until such time as they can become their own advocates. Therefore, training needs are discussed *from the perspective of parents.*

Conference participants identified four salient groups that need training: (1) Parents and Families of Handicapped Persons; (2) Children and Youth With Handicaps; (3) Service Providers; and (4) Parent Organizations and Leaders. Specific training needs of each group were identified, and strategies for addressing those needs were proposed. Their report follows.

Parents and Families of Handicapped Persons

Parents and families of handicapped persons need training in:

- *the law.* This includes (1) learning to use the law to obtain their rights and meet their responsibilities; and (2) gaining an understanding of the need for parent participation in implementing the requirements of the law and current case law.
- *parenting.* This training can range from infant stimulation through preparations for independent living and financial independence through work. Parents also need help in negotiating transitions as their children develop.
- *securing services.* This includes (1) learning to obtain state and local funding for programs and projects; (2) making connections to local resources; and (3) initiating political action.
- *improving services.* Parents must learn to evaluate diagnostic techniques, as well as the educational and related services that their children are receiving. In order to reach these ends, parents must also be trained in communicating and negotiating effectively with service providers.

Therefore, the National Parent RoundTable proposed a number of strategies for addressing parent training needs. They include:

1. Increase the number of funded parent training organizations that are operated and staffed by parents. The focus of these organizations would be on (1) the rights and responsibilities of public agencies, employers, parents and children with handicaps under current legislation; (2) evaluation of implementation of the law; and (3) building good communication skills and good working relationships with professionals.
2. Increase the sharing of information about (1) programs that work; (2) the latest research and theories about human development throughout the life cycle; and (3) parenting. As a part of this effort, the exchange of parent-developed training materials should be encouraged, and a computer data base should be developed and constantly updated.
3. Expand the pool of people concerned with the needs and potential of children with handicaps. This could be accomplished by (1) increased and improved parent surrogate programs; (2) better adoption and foster referral services; and (3) training parents to enlist medical, social service, mental health, government, case advocates and political professionals in the cause of improving the quality of life for persons with handicaps and their families.

Children And Youth With Handicaps

Children and youth with handicaps need training in:

- *the law.* This includes (1) information about the legal rights of persons with handicaps and (2) training in how to use state and local resources and agencies that have responsibilities for implementing the law.
- *reaching their full potential* and *becoming independent, productive citizens.* Such training is obtained through (1) infant stimulation programs; (2) quality educational programs; (3) post secondary educational programs; (4) pre-vocational and vocational training; (5) independent living skills; (6) interpersonal skills, including giving and receiving support from peers with or without handicaps; (7) knowledge about how to be their own advocates with the system; and (8) training state residents for community living.

Therefore, the National Parent RoundTable proposed the following strategies for addressing the training needs of handicapped children and youth:

1. Develop training programs for children with handicaps about their rights and responsibilities. This training should be prepared and delivered at the appropriate level, based on needs, age and comprehension level.
2. Improve programs based on quality practices and expectations that each individual has worth, dignity and potential. Programs should include peer interactions and tutoring, and increased integration of handicapped and non-handicapped individuals. Programs should be designed to cover the whole gamut of life experiences, including better pre-vocational and vocational training and counseling, independent living skills and self-advocacy. Programs for very young children should have strong family and parent involvement. Wherever possible, programs should be built into the regular school curriculum.

Service Providers

Service providers need training in:

- *respecting the dignity of individuals with handicaps and their families.* This includes (1) increased communication skills; (2) improved professional preparation, including a commitment to keep up with advances in their fields; (3) increased investments on the part of formerly peripheral professionals, such as mental health workers; and (4) sensitivity to cultural differences in diagnoses, evaluations, program planning and parental involvement.
- *collaboration and teamwork, especially with parents.* Areas needing increased collaboration include: (1) diagnostic, programmatic and support needs of children with learning disabilities, with emotional or behavioral disorders, and others; (2) the integration of educational and related services programs with the whole of the child's life, including recreation, respite, after school programs, health and other family-centered issues; (4) easing the transition from private or residential to public or community placements; (5) the need to settle and move beyond monitoring and compliance; and (6) contributions parents can make to that effort. This training should also include learning to develop a positive climate for interdisciplinary activities and to communicate without jargon.

Therefore, the National Parent RoundTable proposed a number of strategies for addressing the training needs of service providers.

1. Involve parents as teachers in interactions with the full range of professionals and paraprofessionals.

2. Provide training in (1) attitudes and perceptions; (2) communication; (3) life-cycle of children, youth and families; (4) predictable stress situations and techniques professionals can use that are helpful to individuals and families in stress; (5) collaboration and working as partners; (6) sensitivity to cultural differences; (7) professional rights and responsibilities under the law; (8) professional responsibilities to keep up with the latest developments in their fields; and (9) parental expectations for life-long quality programs. This training should take place at both the pre-service and in-service levels, and should be integrated into certification or recertification requirements.

3. Invest parents and professionals in working together to secure community based resources and support for the evolving needs of individuals with handicaps.

Parent Organizations and Leaders

Parent organizations and their leaders need training in:

- *organizing public awareness programs*. This includes creating new parent groups in areas of the country where they do not exist and/or for populations not currently served (for example, families of newborns, minority families, families living in rural and isolated areas and poor families).
- *funding*. This includes (1) how to obtain funds; (2) how to manage funds; (3) how to tap alternative sources of funds; and (4) how to utilize other resources, including volunteers. This need is a particular problem for established parent organizations.
- *leadership skills*. Such skills include (1) administering the organization; (2) budgetary skills; (3) political skills, including coalition building and networking; (4) advocacy, both on a case-by-case basis and at the state and federal policy levels; and (5) organization and personal survival skills.

Therefore, the National Parent RoundTable proposed a number of strategies for addressing the training needs of parent organizations and their leaders. They include:

1. Experienced parent group leaders should increase the amount of technical assistance that they provide to new parent groups and leaders.

2. Provide parent group organizations with a variety of opportunities to increase their resources. These include (1) increasing levels of funding from federal and state agencies; (2) improving information about alternative sources of funding and about strategies to tap them; (3) sharing information about creative ways to obtain funds from nontraditional sources; and (4) training leaders to influence the resource allocation process at local, state and federal levels.

3. Consider parents as significant actors in the implementation of the law(s), and provide funds for parent training as a matter of social policy on the part of the funding sources. This training might include (1) management and planning skills, (2) organizational survival techniques, (3) inter-organizational collaboration, (4) budgeting, and (5) political action. Parents and parent leaders should be paid for their participation in such training.

In sum, participants in the National Parent RoundTable viewed training as empowering people to use increased knowledge. Because new children with handicaps are being born and diagnosed, there is and will continue to be a need for training in basic information about the nature of disabilities, legal rights, methods of parenting and teaching children with handicaps. Because people learn from experience, there is and will continue to be a need for advanced training in dealing with children as they grow and develop, in dealing with society to insure appropriate and quality services for children, in empowering children with handicaps to deal with their own problems, with society and with one another, and in dealing with the political system that allocates resources in order to insure that appropriate services are available.

Information Needs

Families with handicapped children constantly need information throughout the life cycle of the children. Much research has been conducted on how to make information maximally useful. We have learned that the transfer of information should be carried out by, or direct the receiver to, a person who can help interpret it or expand upon it with additional information. In addition, information must be available when there is a need for it, and it must be presented in an attractive and understandable way. All of these considerations guided the recommendations developed by participants in the National Parent Group RoundTable in order to meet the information needs of parents and families of handicapped children, of children and youth with handicaps, of service providers and of parent organizations and their leaders.

Parents and Families of Handicapped Persons

Parents and families of handicapped children and youth need basic information on:

- the right to life-sustaining treatment for newborns
- the meaning of diagnostic categories and the validity of diagnostic tools
- how to evaluate the quality of programs that have been developed in compliance with the law
- their rights and responsibilities under the law and current case law
- ways to influence programs for their children, including better communication with professionals and policymakers.
- sources of help and support, and
- ways to make society aware of the need for a continuum of comprehensive services from birth through adulthood

Therefore, the National Parent Group RoundTable proposed a number of strategies for meeting the information needs of parents and families of handicapped children. They include:

1. Increase cooperation and collaboration by (1) pooling existing information from all sources and providing it where it is needed and (2) using multiple channels and media for dissemination of the information (for example, electronic mail, print materials, audio/visual materials and expanded use of libraries and other loan systems).

2. Make sure that information which is given to parents reflects the most recent medical advances. This can be accomplished by working with Health Maintenance Or-

ganizations and other health providers, hospitals, pediatricians and university diagnostic and treatment centers, as well as with schools and other community agencies.

3. Create a central information bank, contributing to it and counting on it for timely and comprehensive information.
4. Support parents and families in the movement who have worked hard to bring about the current status of services for children. Also, encourage other parents, families and the community at large to acquire appropriate attitudes about the potential of individuals with handicaps through a broad dissemination of appropriate information.
5. Share information in order to create a general awareness of the political and budgetary processes used by local, state and federal governments.

Children And Youth With Handicaps

Children and youth with handicaps need information

- about growing up and the developmental stages of the life cycle
- to empower them to make informed choices of their own
- from and about their handicapped and non-handicapped peers about successful coping strategies that will help them create positive self-images
- that will help them reach their potential and become productive, independent members of society
- about sexuality, nutrition, creative problem solving, and about coping with schools and parents from the perspective of their own special needs

Therefore, the National Parent Group RoundTable proposed a number of strategies for addressing the information needs of children and youth with handicaps:

1. Identify, develop, create and find information about life changes as children and adolescents mature. Share that information with them and their families.
2. Establish a nation-wide forum for communication between and among individuals with handicaps. In order to accomplish this goal, investigate peer counseling programs and "buddy" programs that are being used for more effective mainstreaming.
3. Encourage and support families as they experiment with independence for their members, including providing necessary information about resources and support groups.

Service Providers

Service providers need information

- from parents about their children and their families, including information about developmental, life cycle changes
- about state-of-the-art research on handicapping conditions and quality practices
- about the processes of collaboration and ways to work and communicate better with parents and other professionals
- about changing attitudes and the predictive power of expectations
- about community action and the process by which society allocates resources
- about cultural differences and values between minority and majority populations

Therefore, the National Parent Group RoundTable proposed the following strategies for meeting the information needs of service providers:

1. Continue to support one another in maintaining the philosophical position that parents and families are important, expert and integral members of the treatment/education team concerned with children.
2. Encourage professionals to obtain information about current provisions in federal and state law, including informed and consistent parent involvement in decisions. Use committed professionals to enlist the support of their non-informed colleagues.
3. Encourage professionals to cooperate with and provide information to staff of personnel training programs and of local institutions.
4. Use state, regional and national meetings of professional associations to facilitate inter-disciplinary information sharing.

Parent Organizations And Leaders

Parent organizations and their leaders need information

- from peers, regarding solutions to common problems
- about techniques of practices that have proven effective (for example, in the policy area, influencing the passage of or implementation of legislation)
- about the formation, maintenance, management and support of voluntary organizations
- about changes, or contemplated changes, in policy or legislation that will effect their families, so that they can plan an action response
- about ways to evaluate information for veracity (particularly, controversial or experimental treatment proposals, but also ways to evaluate the quality of programs and practices)
- about successful community involvement programs and projects
- about the needs and cultures of unreached parents, so that all parents, regardless of ethnic background or economic status, can be supported and their families assisted
- about leaders' personal survival and self-renewal

Therefore, the National Parent Group RoundTable proposed a number of strategies for addressing the information needs of parent organizations and their leaders. They include:

1. Plan an agenda on a national level with substantive involvement from experienced parent leaders to address questions of (1) revisions of law and regulations, (2) provision of current and needed services, (3) funding appropriations at the state and federal levels, and (4) integration of programs leading to a continuum of services from birth throughout life.
2. Collect information about existing reseach and data on the efficacy of special education and other services for children and youth with handicaps. This would allow parent organizations to (1) recommend additional areas for inquiry and (2) share existing information with policy makers and the general public.
3. Continue to evolve a helpful and supportive role for the National Information Center for Handicapped Children and Youth, including new ways to more effectively exchange print and human resource information.

Implications For Future Resource Allocations

The participants in the National Parent Group RoundTable concluded their discussions with a set of recommendations about needed changes in funding decisions about programs and services intended to address the training needs of handicapped children and youth and their families. The funding discussion assumed two thrusts. the need for increased resources and the need for wiser, more rational uses of existing resources. Funding for programs and services may come from federal, state or local public agencies and/or from private sector resources on a corporate or individual level. This discussion recognizes the contribution that each level can make, and the responsibility that each level has.

A major theme of this conference was the need to provide services to handicapped individuals and their families, from birth throughout the life cycle. That may mean relatively short term infant stimulation programs or mother/child nutrition programs. It includes pre-school and K-12 educational programs in the least restrictive environment, as well as recreation, respite and related services where necesesary. Importantly, all programs should be of demonstrable high quality, and should involve parents and families *centrally* in the decision making.

In addition, pre-vocational and vocational programs are necessary for preparing productive citizens, as are community-based independent and supported living programs, with the appropriate training for both residents and staff. Institutionalization or reinstitutionalization are placements of last resort. Also, support should be provided for children, regardless of their ethnicity, family income, or family circumstances, and additional programs for surrogate parents, foster parents, adoptive parents and case advocates are indicated. Adjudicated youth should be provided with appropriate educational and social service programs. Finally, post-secondary education, including vocational schools, community colleges and institutions of higher education, have an important role to play in preparing young people with handicaps for their future lives.

Parents of handicapped children need support from society for their difficult role. This support should include training and the funding that will enable them to participate in training (including reimbursement for babysitters and transportation). Such support must also include recognition of parents' expertise and their unique roles as master teachers and case managers for their children. Thus, parents should be encouraged and supported to come together to interact with one another, with professionals of every type, and with policy makers in order to provide expert formal and informal testimony on the needs, problems and triumphs of their children and families. In addition, parents perform an important service in monitoring implementation of laws and regulations, and that role should be recognized and rewarded.

It is time to pause and to reassess the ways in which resources are currently being allocated. How responsive are they to the training and information needs that have been articulated by participants in the National Parent Group RoundTable? In what ways can existing resources be reallocated to address these needs? Finally, what additional resources can be garnered from both the public and private sectors to address these needs? It was suggested that policy makers use the answers to these questions as planning guides as they define future directions in the provision of programs and services to handicapped children and youth and their families.

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With this newsletter, The National Information Center for Handicapped Children and Youth is inaugurating a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209.